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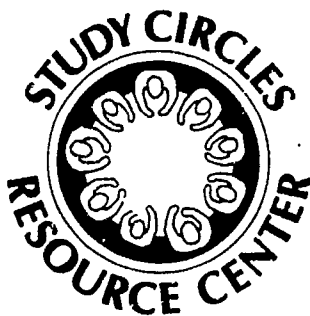
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ABSTRACT

This program guide on the right to die provides policy issue information where ethical concerns have a prominent place. Three positions about the right to die are presented: (1) mercy killing and assisted suicide should be legally permitted in certain cases; (2) legal status should be given to living wills and other advance directives that would allow people to die with dignity, but mercy killing and assisted suicide should be legally prohibited; and (3) both mercy killings and allowing patients to die by withholding life-saving treatment should be legally prohibited. In addition to an introductory letter, this guide includes the following information: (1) the right to die--a framework for discussion; (2) a summary of the positions; (3) an examination of the positions; (4) glossary; (5) supplemental reading; (6) your continued involvement in this issue; (7) suggestions for leading this discussion; (8) leading a study circle; (9) suggestions for participants; (10) follow-up form; and (11) Public Talk Series Programs and other resources available from the Study Circles Resource Center. (NLA)

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Public Talk Series

THE RIGHT TO DIE

October 1991

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*"History, theology, and philosophy will show that
every enlightened civilization has had a sense of
right and wrong and a need to try to distinguish
them."*

Michael Josephson, ethicist
from Bill Moyers' *A World of Ideas*

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*Material to be duplicated for participants

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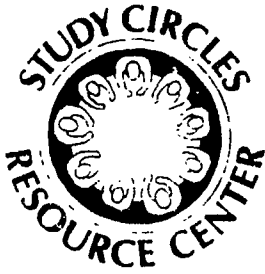
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Please write the Study Circles Resource Center at PO Box 203, Pomfret, CT 06258, call (203) 928-2616, or FAX (203) 928-3713 for more information on study circles and the Study Circles Resource Center.

September 1991



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In a democracy, it is crucial that the public have input into the decisions government makes. Citizens must listen to a variety of viewpoints, consider the consequences of all positions, and make hard choices. The Study Circles Resource Center's Public Talk Series is based on this belief. The programs of the series are designed to assist in the discussion of critical social and political issues; each offers a balanced, non-partisan presentation of a spectrum of views.

The Right to Die provides the information your group will need in order to hold a discussion on a special kind of policy issue – one in which ethical concerns have a prominent place. Such issues are especially difficult to grapple with since people's deeply held beliefs come into play, and yet there are few opportunities to reflect on these beliefs in an impartial setting. As medical technology continues to advance, decisions about life-prolonging treatments are becoming more complicated. Society is being forced to come to grips with the value questions that are raised by new circumstances; attention to public policy on the right to die is increasing as courts across the country make rulings on precedent-setting cases. We encourage you to invite your organization's members, friends, neighbors, and co-workers to join with you in a discussion of this difficult issue.

A summary of the material

Three possible positions about the right to die are at the heart of this program:

Position 1 – Mercy killing and assisted suicide should be legally permitted in certain cases.

Position 2 – Legal status should be given to Living Wills and other advance directives that would allow people to die a natural death with dignity, but mercy killing and assisted suicide should be legally prohibited under all circumstances.

Position 3 – Both mercy killing and allowing patients to die by withholding life-saving treatment should be legally prohibited, even when requested by those who are competent and terminally ill.

These positions are the starting point for a highly participatory discussion in which a leader assists participants in grappling with the issue of the right to die. Although the arguments for and against these positions are primarily of an ethical nature, each position advocates a distinct public policy.

Organizing a small-group discussion on this issue

The positions and the supporting material are designed for use in a single-session program of approximately two hours. The organizer will need to recruit between 5 and 20 participants, decide on a time and place for the meeting, select a discussion leader, photocopy the materials (participants will need copies of items marked with an asterisk in the table of contents), and distribute them to participants. If there is not enough time to mail information to participants prior to meeting, the components that should be handed out during the meeting are "A Framework for Discussion," "A Summary of the Positions," "Suggestions for Participants," and the "Follow-up Form."

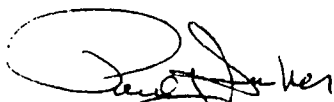
The organizer's most important task is choosing the discussion leader. This person need not be an expert on the subject being discussed, but should have some familiarity with it. The leader should be able to encourage participants to freely express their thoughts while preserving some focus to the session as a whole. A commitment to balance and impartiality is essential. Included for the leader's use are "Suggestions for Leading *The Right to Die*" and "Suggested Discussion Questions." The leader should also read carefully the general suggestions in "Leading a Study Circle." (Please see the back cover of this packet for information on additional resources on organizing and leading study circles available from SCRC.)

Organizing further discussions

The Study Circles Resource Center (SCRC) makes this material available in part to encourage discussion of this particular issue; our end goal, however, is to encourage citizen debate on the wide range of issues – whether local or national – confronting our society. We hope that the use of this material will inspire your group to become a "study circle," meeting regularly to discuss issues of common concern.

Several options are available to groups wanting to carry on to discuss other issues. See the back cover of this packet for a list of other programs in the Public Talk Series. Also noted on that page is SCRC's clearinghouse list of discussion programs developed by a variety of organizations. If your group would like to take on an issue for which no ready-made discussion package is available, a few good newspaper or magazine articles can provide the basis for dialogue. Please call us at SCRC for advice on developing your own study circle material.

We invite you to take part in the richly rewarding discussion that can result when you meet with your peers, associates, friends, and neighbors in small, informal gatherings to discuss the concerns of our society. And we encourage you then to communicate the outcomes of your discussion to relevant policymakers, for only then can your informed judgment influence policy.



Paul J. Aicher
Chairman

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A Framework for Discussion

When asked to contemplate whether there are any circumstances under which it would be morally permissible to end someone's life out of considerations of mercy, among the most compelling and persuasive cases brought to mind are those similar to the following one described by journalist Stewart Alsop, during his treatment for terminal cancer:

The third night that I roomed with Jack in our tiny double room in the solid-tumor ward of the cancer clinic of the National Institutes of Health in Bethesda, Md., a terrible thought occurred to me.

Jack had a melanoma in his belly, a malignant solid tumor that the doctors guessed was about the size of a softball. The cancer had started a few months before with a small tumor in his left shoulder, and there had been several operations since. The doctors planned to remove the softball-sized tumor, but they knew Jack would soon die. The cancer had metastasized – it had spread beyond control.

Jack was good-looking, about 28, and brave. He was in constant pain, and his doctor had prescribed an intravenous shot of a synthetic opiate – a pain-killer, or analgesic – every four hours. His wife spent many of the daylight hours with him, and she would sit or lie on his bed and pat him all over, as one pats a child, only more methodically, and it seemed to help control the pain. But at night, when his pretty wife had left (wives cannot stay overnight at the NIH clinic) and darkness fell, the pain would attack without pity.

At the prescribed hour, a nurse would give Jack a shot of the synthetic analgesic, and this would control the pain for perhaps two hours or a bit more. Then he would begin to moan, whimper, very low, as though he didn't want to wake me. Then he would begin to howl like a dog.

When this happened, either he or I would ring for a nurse, and ask for a pain-killer. She would give codeine or the like by mouth, but it never did any real good – it affected him no more than half an aspirin might affect a man who had just broken his arm. Always the nurse would explain as encouragingly as she could that there was not long to go before the next intravenous shot – "Only about 50 minutes now." And always poor Jack's whimpers and howls would become more loud and frequent until the last blessed relief came.

The third night of this routine, the terrible thought occurred to me. "If Jack were a dog," I thought, "what would be done with him?" The answer was obvious: the pound, and chloroform. No human being with a spark of pity could let a living thing suffer so, to no good end. (Stewart Alsop, "The Right to Die With Dignity," *Good Housekeeping*, 1974.)

Is there a right to die with dignity, as the title of Alsop's article suggests? If so, what is its basis and what are the conditions under which a person is morally justified in exercising this right? Further, what are the duties that would correspond to the right to die? For example, if there is a right to die, does it

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include the obligation on the part of others to provide aid-in-dying for those who wish to end their lives? Or, does this right merely require that no one interfere with another's decision regarding death?

Along with these considerations are important questions about who should decide for our society whether there is a right to die with dignity and what that means in practice. What should be the role of government (typically thought of as the only institution with a valid claim to representing all of society) in enforcing any decision? For example, should there be laws that allow not only for the withholding of life-saving treatment, but also permit mercy killing and assisted suicide? Or, should there be laws that prohibit one or all of these actions?

There are many complexities involved in answering these questions; they touch on our basic hopes and fears about life and death. In addition, there are difficulties in coming to common definitions — how do we even determine whether an act constitutes an act of "mercy killing" or assisted suicide? These complications can be further illustrated by considering the following cases:

A 90-year-old man with no known family has severe pneumonia; he requests a ventilator to assist him in breathing. After being told that his room in a welfare hotel has been rented to someone else, he requests that the ventilator be removed. Should his doctors grant the request?

A 60-year-old woman who has been in failing health over the past two years is told that she has terminal cancer of the liver. She is distraught, but seems to accept her fate and makes plans for the eventuality of her death. By signing a Living Will (see glossary), she expresses her wish to have life-sustaining treatment withheld if the burdens of treatment outweigh the benefits, and has

made it clear that she does not want to be resuscitated if death is imminent and she suffers cardiac arrest. A copy of this document is on file in the hospital when the patient is brought in to the emergency room after she is discovered unconscious, having slit her wrists and swallowed a bottle of tranquilizers. Should the emergency room physicians be required to attempt to revive the patient?

A 52-year-old woman, who had suffered a cerebral hemorrhage four years earlier, is now irreversibly comatose. With the use of artificial life-support systems, she can be kept alive indefinitely. Her family asks that the intravenous feeding tubes being used to supply her nutrition and hydration be removed so that she may be allowed to die a natural death with dignity. The family claims that they are making the decision she would make if she were able, even though she never made clear what she would want done if she were to lapse into a comatose state. According to them, she was so vital and placed such a high value on an active mental life that she would be horrified at what is being done to keep her body functioning. Should the hospital be allowed to remove the feeding tubes from this patient at the request of her family?

A 25-year-old man has been severely injured in an explosion. The young man, who was once a star athlete, is now blind, deaf in one ear, grossly deformed due to burn scars, and a double amputee as a result of gangrenous limbs that were removed when infection from the burns could not be controlled. This patient repeatedly refused treatment, but was nevertheless treated against his will. A year after being released from the hospital, he is still adamant that he

wants to die. He asks his brother on several occasions to take his hunting gun and shoot him. Given that the medical community has failed to grant his requests to forego treatment and let him die, should the man's brother be free from prosecution if he consents to the burn victim's request?

On the day they brought their first child home, a couple left the hospital with a daughter who was seriously deformed. She had a misshapen skull, her arms and legs had failed to develop, her large intestine emptied into her vagina, and she had no muscular control over her bladder. That evening, the child died from a lethal dose of tranquilizer put into her formula by her mother. The couple said the fact that their daughter had a normal brain and would know her fate led them to the decision that they "couldn't let her live like that." Did the couple make the right decision?

Which of the cases presented above constitutes mercy killing or assisted suicide? Which are morally permissible? Which should be legally permissible? These cases introduce a range of ethical concerns and policy questions regarding the right to die. There are no easy answers to the questions raised by these cases. In fact, they are not presented in order to draw out definitive answers, but rather because they cause us to reflect on our most basic beliefs about how we should be allowed to live and to die. As new technologies are developed and society is faced with new choices about the meaning of the right to die with dignity, it is hoped that considering these issues with others will help promote a deeper understanding of the nature of moral conflict. The resolution of these conflicts, leading to the adoption of certain policies, will reflect which ethical principles we regard as paramount.

The decisions we would make in these cases are influenced by reason and by deeply held beliefs about the meaning of life, the meaning of death, and the importance of individual autonomy (see glossary). The emotions of fear, compassion, sorrow, anguish, and perhaps even contempt and disgust will also play a part. Whether we think that life is valuable in and of itself or, on the other hand, that the value of life is instrumental (that is, that life is valuable only because it is able to provide the experiences we consider worthwhile) will no doubt influence our perceptions of death and the importance we place on the quality of life. In cases in which life can no longer provide the experiences that we regard as meaningful, death may not be considered an evil. While some deaths are indeed tragic ones, some lives might be considered tragic as well. In both cases the tragedy is a result of thwarted aspirations, plans that will never be carried out, work that will never be done, and relationships cut short or never developed.

Is This Life Worth Living? Who Decides?

Because we are confronting moral dilemmas within the area of medical ethics, many of the questions that are raised must be viewed in the context of the relationship between patients and health care professionals. The moral conflicts that arise in this setting are often a result of differing attitudes about how to resolve disputes when the perceived rights of patients clash with the perceived duties of doctors, nurses, and administrators. In many cases health care professionals approach medical decisions differently than do patients and their families. A difference in perspective often leads to conflicts concerning what is in the patient's best interest (see glossary) and who should be allowed to decide what will promote it. The doctor's medical expertise enables him or her to better predict physiological outcomes of treatment or the refusal

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of treatment. In this sense, the doctor is in the best position to determine how likely it is that medical intervention will promote *physical* well-being — that is, improved health if possible or, at the least, the preservation of life.

However, only the patient can determine the extent to which delaying death will contribute to his or her *overall* well-being. From the patient's point of view, well-being may be largely a function of self-determination, which the doctor may wish to override "for the patient's own good." Of course, it is natural to want as much control over one's death as one would want over any other event or process in life. In fact, it was the fear of not being allowed to control this event that, last year, led Janet Adkins to enlist the aid of Dr. Jack Kevorkian to create a suicide machine for her after her diagnosis with Alzheimer's disease. Her realization that eventually she would not be able to do what gave her life meaning or be competent (see glossary) to decide for herself how she wanted to die forced a decision that some saw as tragic and premature and others regarded as reasonable and life-affirming. Her case brought a public policy question to public attention: should actively assisting someone in dying ever be legally permissible?

For some patients, unlike Janet Adkins, taking control of one's destiny means relinquishing responsibility by giving permission to the doctor to do whatever he or she thinks best. Giving the doctor complete authority is, therefore, not necessarily inconsistent with respecting a patient's autonomy. However, at times there *are* conflicts between patients and health care professionals regarding the right to die; these conflicts generally take two forms. First, there are those cases in which the patient or the patient's family wants to refuse or discontinue treatment even though the doctor thinks the

patient will be benefitted by the treatment. Second are cases in which the patient or the patient's family wants treatment to be continued even though the doctor believes the treatment will be futile. (The second type of case occurs more frequently than the first, but receives much less public attention.)

The cases described earlier represent only a few of the many kinds of situations that happen each day calling for decisions about life-saving treatment. These complex and difficult decisions are often made without the luxury of time to assess the alternatives. This is one of the reasons it is important to give thoughtful consideration to the issues before we are confronted by them in our personal lives. As individuals and as a society we are faced with many questions, among them the following:

- To what extent should individual finances enter into decisions about life-saving treatment? Should society put limits on how much it will pay for this kind of treatment? In light of scarce resources, who should decide when the costs of treatment outweigh the possible benefits?
- Is respecting a patient's autonomy always the most important aspect of providing good medical care, or are there other duties that take precedence over a patient's decision to have his or her life ended?
- When is letting someone die equivalent to assisting in the person's suicide?
- Are mercy killing, suicide, or assisted suicide ever morally permissible?
- To what extent is an ill person's desire to die influenced by whether most people in society would consider life under their particular circumstances worth living?

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- Would allowing mercy killing and assisted suicide lead to a perceived "duty to die"?
- Should society do more to ease the burdens on the families of those who cannot care for themselves or is this a private matter in which the state should not intervene?

Talking About The Right To Die

In weighing the issues surrounding the right to die, it will be useful to be familiar with certain frequently used terms. The term *euthanasia* is derived from the Greek words meaning "good death." Users of the English language have adopted the phrase *mercy killing* as its closest synonym.

In its broadest sense, *euthanasia* is the *intentional taking of another's life or the hastening of death by withholding of treatment that could prolong a person's life, out of considerations of mercy.* Within this broad characterization, we can distinguish two types of euthanasia — *active* and *passive*. When someone acts to end another's life from merciful motives, the person has committed what is referred to as *active euthanasia*. On the other hand, when one refrains from acting in order to hasten death, the result is termed *passive euthanasia*.

Until recently, euthanasia was commonly used to refer to the allowing or causing of death when all of the following specific conditions were met:

- The person whose life is ended is terminally ill.
- The person is suffering from a great deal of pain.
- The person will die soon anyway.
- The person requests death as a means to end suffering.

- The one who complies with the request for death does so from merciful motives.

However, with increasing frequency there are cases in which one or more of these conditions is not met but which many would classify as instances of euthanasia. For instance, ventilators and feeding tubes are often removed from patients who are irreversibly comatose in order to allow them to die a natural death with dignity. Because these cases involve the withholding of treatment in an effort to hasten death, they seem to fall under the category of passive euthanasia. Yet most comatose patients are not terminally ill, nor are they thought to be suffering from pain. In addition, these individuals are not in a position to request death and may never have specified their wishes for such a contingency ahead of time. Should these be regarded as cases of euthanasia? The answers we give to this question are likely to be a reflection of our attitudes about whether mercy killing and suicide are ever moral.

In the case of incompetent individuals, the decision to forego or discontinue treatment is either made by them prior to their falling into the comatose state or it is made by someone else. This leads us to draw another distinction between various forms of euthanasia. Euthanasia is termed *voluntary* only when it is requested by a person who is competent to make decisions with respect to his or her own life. When a person's life is ended from merciful motives without his or her consent, euthanasia is either *nonvoluntary* (when a person is not able to give rational consent) or *involuntary* (when it is done against the person's wishes).

There are vast number who fall into the category of "incompetent." Among them are: infants and children; those suffering from insanity, dementia, and senility; the severely retarded; and the comatose. Advances in

medical technology and more frequent intervention to prolong life have dramatically added to the number of incompetent patients. Who should be allowed to make decisions concerning their treatment? Do we have the right to make quality-of-life decisions for others? Do we attempt to determine what is in the best interest of those who are incompetent by attempting to make the best possible judgment about what they would choose if competent?

Living Wills and Other Advance Directives

The plight of many incompetent individuals and their families was brought to national and international attention in the 1970s by the Karen Quinlan case and more recently by the Nancy Cruzan case, decided by the U.S. Supreme Court in 1990. Both women suffered trauma that left them in what doctors judged to be irreversible comas. Both had families who requested that their daughter be allowed to die without the intervention of artificial life-support. The Quinlans petitioned on behalf of their daughter to have her treatment withdrawn, on the grounds that being kept on a ventilator was an unwanted bodily invasion and therefore violated her right to privacy. They also requested that no extraordinary measures be used to keep Karen alive, including the administration of antibiotics. The Cruzans went even further in testing the courts, by petitioning to have Nancy's nutrition and hydration tubes removed. In both cases, the families eventually won the right to refuse treatment and to have their daughters die natural deaths. Opponents of the decisions argued that these women, who were emotional and financial burdens and could not even make their own preferences known, did *not* die "natural deaths." In fact, according to this argument, there was little or no difference between letting them die and killing them.

These cases had an enormous influence in drawing attention to advance medical directives and to right-to-die legislation. In 1975, before the Quinlan case, only 5 states had introduced right-to-die bills (giving legal status to Living Wills). Currently, 42 states (as well as the District of Columbia) have Living Will legislation; legislation is pending in the other 8 states. Documents such as Living Wills and Durable Powers of Attorney for Health Care (see glossary) allow individuals to state, while competent, what they would want done or who they would want to make decisions for them if they were no longer in a position to decide for themselves. These advance directives provide important decision-making guidelines; whether these documents should be legally binding is one of the policy debates surrounding the right to die. Some would like to see their force strengthened by giving them legal status. Others claim that such directives should not be legally binding, given that a great deal may change in terms of medical developments and in a person's life between the time the document is signed and the time at which it would be enforced.

Increased attention to Living Wills and other advance directives during the past decade is also due to the diseases from which people are dying in increasing numbers. The American Cancer Society tells us that three out of four families will be touched by cancer. In addition, more and more people are dying from AIDS. It is predicted that more than a million people will be infected with this disease by the year 2000. The horrible deaths frequently experienced by victims of both of these diseases has led to increased requests for help in dying; this has led to some calls for going beyond Living Will legislation to develop guidelines for a national policy on euthanasia. In fact, while the subject of euthanasia was rarely addressed in medical journals two decades ago, discussions of it are now quite common. Whatever one's opinion about this controversial subject,

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there has been a growing public consensus that medical professionals, trained to prolong life, are often ill-prepared to deal with their patients who are dying.

The Future Is Not Like It Used To Be

Proportionately, the fastest growing age group in the United States is the over-85's. In the past two decades, the amount of the federal budget spent on the elderly went from 15% to 28%. By the year 2000, we can expect to spend \$200 billion on medical care for those over the age of 65 [Bonnie Angelo, "Examining the Limits of Life," *Time*, November 2, 1987, p. 76.]. This is part of a steady trend toward a health care crisis in America.

For many elderly and chronically ill patients, it is already the case that "the future is not like it used to be." Instead of being cared for and dying at home, 80% of Americans now die in hospitals [President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, DC: Government Printing Office, 1983), pp. 17-18.] Thus, most of the money spent on a person's health care for his or her lifetime is spent during the last six weeks of the person's life. These facts signal the need to make decisions concerning the allocation of scarce medical resources. Indeed, some states (such as Oregon) have proposed plans for rationing. The proposals include: not using respirators for the dying; prohibiting the use of Medicare payments for certain procedures (such as organ transplants, kidney dialysis, and by-pass surgery) for the elderly; and a ban on extraordinary means (including resuscitation, artificial feeding tubes, and costly antibiotics) for the terminally ill and those in irreversible comas. Critics contend that such plans shift the emphasis from the right to die to a "duty to die."

Yet our society literally cannot afford to ignore financial costs as a factor in determining what kinds of health care ought to be provided for patients. There are increasingly heavy economic burdens to bear as a result of advances in medical technology. Consider, for example, that each year pulmonary specialists save thousands of ventilator-dependent patients, most of whom are conscious. Many of these patients, who are not necessarily terminally ill, will need more care than is usually available in nursing homes though they do not require the level of care provided by hospitals. Very few families are able to provide care in the home for these patients. So what is to be done when hospitals insist that the patients be released? Who is to bear the cost in terms of medical and economic resources? Whether society is willing to help provide the necessary long-term care will, in many of these cases, affect an individual's decisions about whether life is worth living.

Decisions to forego treatment are not always a matter of the patient's choice; they are sometimes dictated by limited resources (for example, any hospital has only a limited number of ventilators). As a society we must establish the limits and priorities of life-saving treatment and of aid-in-dying, unless we are willing to have these choices prescribed for each of us by our particular circumstances.

A Summary of the Positions

Position 1 – Mercy killing and assisted suicide should be legally permitted in certain cases *because*:

- Those who do not or would not want to continue living and whose conditions are not likely to improve should be allowed the option of painless, humane, and dignified deaths.
- Principles of mercy and beneficence (see glossary) require that we prevent suffering by not allowing people who request a quick and painless death to endure a slow and agonizing one.
- Death is neither harmful nor violates the right to life of individuals who request death when continued existence no longer proves beneficial nor meaningful.
- Killing is no worse than hastening death by withholding treatment when one is motivated by mercy and death is certain to result in either case.
- The quality of one's life is more important than the amount of time lived.
- The prohibition against mercy killing and assisted suicide often results in needless suffering along with increased emotional and financial burdens.
- The state should not be allowed to limit the free, rational, self-regarding actions of individuals to determine their means of death.
- Public opinion favors allowing physicians to provide aid-in-dying through mercy killing or assisted suicide at the request of the patient.
- Legalization would simply reflect the sympathetic attitude about mercy killing that is already prevalent in the courts.

Position 2 – Legal status should be given to Living Wills and other advance directives that would allow people to die a natural death with dignity, but mercy killing and assisted suicide should be legally prohibited under all circumstances.

Legal status should be given to Living Wills and other advance directives that would allow people to die a natural death with dignity *because*:

- The right to die includes the right to refuse bodily invasion and forced intervention, but does not include the right to demand death.
- There is no moral obligation to provide treatment that is futile or to save the lives of those who will either suffer chronic, debilitating illnesses or remain irreversibly comatose.
- Our society's over-reliance on medical technology has led to the breakdown of humane, family-centered medicine and to its replacement with a technological science of medicine.
- The right to refuse treatment, even at the cost of one's life, is a fundamental right derived from the rights to privacy, liberty, and autonomy.

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But, mercy killing and assisted suicide should be legally prohibited under all circumstances *because:*

- Allowing active euthanasia and assisted suicide would signal a devaluing of human life that would lead to other forms of killing, with the potential for the kind of social policy adopted by the Nazis.
- There is no adequate means for guarding against abuse and ensuring that a free and rational decision has been made in a policy that allows active euthanasia and assisted suicide.
- Allowing active euthanasia and assisted suicide would lead to the deaths of falsely diagnosed patients who would have recovered if refusal of treatment alone were allowed.
- A policy permitting active euthanasia and assisted suicide would foster the sense that there is a duty to die as opposed to a right to die.
- Doctors and nurses, who would be the most likely to perform acts of euthanasia and assisted suicide, take oaths requiring them to do no harm and to respect life. To allow their participation in such acts would undermine trust in the medical profession.
- The intentional killing of an innocent human being, despite the person's request, is always wrong.

Position 3 – Both mercy killing and allowing patients to die by withholding life-saving treatment should be legally prohibited, even when requested by those who are competent and terminally ill *because:*

- All human life is sacred and should be preserved at all costs.
- The right to life overrides all other rights, including the right to die.
- Withholding life-saving treatment when the benefits are very uncertain leads to the unnecessary deaths of some who would have benefitted if aggressive therapy had been required.
- Foregoing life-support and refusing treatment in many cases is simply a form of suicide.
- The liberty of persons does not entitle them to end their own lives or the lives of other innocent human beings.
- Allowing people to die has already placed us on a slippery slope toward disaster, signaled by the fact that providing food and water for patients who cannot nourish themselves is now considered extraordinary treatment in some cases.
- Many patients who have been allowed to die suffered slow and difficult deaths, not the dignified deaths for which they were looking.
- Life should be maintained regardless of the cost, the physical condition of the patient, or the chances of recovery.
- Doctors should not be allowed to play God with people's lives.

An Examination of the Positions

Position 1 – Mercy killing and assisted suicide should be legally permitted in certain cases.

People should be allowed the option of painless, humane, and dignified deaths when they are dying or irreversibly comatose, or when the burdens of continued existence make it such that they no longer consider their lives worth living and conditions are not likely to improve. It is unfortunate that society imposes a choice on doctors: either ignore the pleas of the suffering and the expressed will of those who can no longer speak for themselves, or face criminal prosecution if you consent to end their pain. Considerations of mercy and principles of beneficence dictate that active euthanasia and assisted suicide should be legally permitted in certain circumstances.

Killing vs. letting die. Current medical and legal practice reflect the attitude that killing a terminally ill or irreversibly comatose patient is always worse than letting the person die. Both the law and the American Medical Association sanction the withholding of treatment in order to prevent prolonged agony for the terminally ill. Yet, at the same time, they forbid assisting in death by prescribing or administering a lethal dose of pain medication. A policy that allows people to slowly wither away, starve, or suffocate in the name of "a natural death with dignity" but prevents mercy killing in order to avoid the charge of causing death has no sufficient moral basis and results only in suffering, wasted efforts, the fostering of false hope, and financial hardship for many individuals and their families.

The terminally ill. Consider first the claim that morality requires that we not grant requests from the terminally ill for active eu-

thanasia. How is assisting in death worse than hastening death by failing to provide aggressive treatment? There is nothing morally significant about the fact that in active euthanasia death is brought about by acting, as opposed to refraining from acting. Allowing someone to die (as defined in most current legal and professional standards) can involve direct action too – for instance, if one "pulls the plug" on life-support for a patient. Further, in both active euthanasia and allowing a terminally ill patient to die, the patient's death is intended as a means to ending the person's suffering. The motivation in each case is mercy. Finally, death is certain to result in both cases. Therefore, unless there is some morally relevant distinction between active and passive euthanasia that makes active euthanasia worse, we should not use the grounds that killing is always worse than letting die to prohibit active euthanasia for the terminally ill.

The irreversibly comatose. Patients who are irreversibly comatose are not necessarily terminally ill, but there is no medical hope of recovery for them. The legal and medical duty to respect a patient's right to refuse life-saving treatment under certain circumstances has been extended to those who are not terminally ill but are incapable of living under their own power. Some, who have made their wishes known through Living Wills and advance directives, have exercised the right to die by ordering in advance that their respirators should be turned off or that their feeding tubes should be removed. In other cases, family members or court-appointed guardians have also been allowed to make a "substituted judgment," refusing treatment on

the patient's behalf and thereby hastening the deaths of those who never expressed their desires when they were able or who were never able to decide for themselves (e.g., infants, the severely retarded, and the insane). Since the law permits the starvation and dehydration of the irreversibly comatose, what social benefit could there be in prohibiting lethal doses of medication? In fact, since we cannot be sure that the comatose are incapable of suffering, it would seem morally compelling to ensure that we take precautions against this possibility.

The quality of life. Not all acts of killing should be considered harmful. In our reverence for life, we mistakenly attach importance to the amount of time lived instead of the quality of that life. Considerations of the quality of life are at least as important. One of the reasons the direct, intentional killing of a person is considered such a grave harm is that we are depriving the person of something that is valued above all else — namely, the person's life. But when a person no longer considers life worth living because it involves a continuous state of pain, humiliation, or total dependency, the benefits of continued existence might be outweighed by the burdens. In these instances, death would not be as harmful as continuing to live. To be harmed by death requires that there is some benefit to be gained by continuing to live. Thus, the irreversibly comatose will not be harmed by death either, since they are not in a position to be burdened or benefited by continued existence. However, since their families are capable of suffering emotional and financial losses, and because medical resources are scarce, making provisions for quick and painless deaths in these instances has social benefits.

The right to life. Just as not every act of intentional killing is harmful to the person killed, not every act of killing violates the individual's fundamental right to life. A right

is violated only when we take it away against the will of the person who possesses the right. If a person willfully abdicates his or her rights, these rights are not violated when they are taken away. A person who voluntarily asks to be killed in order to have his or her suffering ended would not, therefore, have the right to life violated through active euthanasia. Nor would a person who makes provisions for aid-in-dying while competent by expressing the desire to have his or her life actively ended if it were reduced to that of a persistent vegetative state (see glossary).

Considerations of personal liberty. If a person makes a free and rational choice to end his or her life in order to prevent further suffering or, while competent, establishes the desire to have another assist him or her in dying if the person can no longer speak or act on his or her own behalf, the state has no right to interfere. Even if active euthanasia and assisted suicide are considered immoral by some, the law should not interfere with a competent adult's self-regarding actions. The state should limit only certain types of actions: those that are not fully rational, not fully voluntary, or likely to lead to the harm of another. Even though any person's decision to die is likely to harm others, the individual's liberty should be limited only if the benefits of limiting it will outweigh the harm of failing to limit it. In other words, the harm brought about by restricting the person's actions must not be greater than the harm prevented by limiting the person's freedom.

Every dying patient should be allowed to choose or reject euthanasia as a matter of personal liberty. In addition, all competent individuals should be allowed to make legal provisions enabling others to assist them in ending their lives if they are documented to be in an irreversible coma. After all, it is the patient's life and no one else's.

Underlying Principles and Assumptions

1. The value of life is dependent upon its quality. Thus, the right to life should not be interpreted as the right not to be killed, but instead as the right to live at a certain minimum standard of quality. The person's right to life is not violated, then, by killing the person when the person perceives his or her life as having fallen below this minimum standard and consequently asks to be killed out of considerations of mercy. The same is true for those who are no longer in a position to request death and yet have previously established the desire to have their lives ended under certain circumstances.

2. Physicians have a duty to relieve suffering along with the duty to preserve life. When there is a conflict between these two duties, the patient or his or her surrogate, the patient's family, and the doctor are entitled to resolve the conflict to bring about whatever course of action is best for the patient. For humane reasons, a doctor should be allowed, with the informed consent (see glossary) of the patient, to alleviate severe and prolonged suffering. It is often the case that terminally ill patients die as a result of the adverse side-effects of pain medication that is administered in increasingly frequent and intense doses. Rather than consign patients to a "state of narcotic stupor" for the remainder of their lives, we should allow doctors to alleviate suffering in a manner that is consistent with human dignity.

3. Principles of beneficence and mercy require that we do not permit people without hope of recovery from suffering prolonged and agonizing deaths. It is cruel to allow a human being to linger for months in the final stages of agony, weakness, and decay. It is also cruel for their loved ones to have to endure this process. We should extend the same level of compassion to human beings that we would grant to an injured and dying animal.

4. When the intention is the patient's death, the motivation is mercy, and death is certain to result whether one acts or refrains from acting, it is no worse to cause death by acting than to hasten death by failing to act.

5. Whenever charges have been brought against those who have performed active euthanasia, prosecutors have had a difficult time securing convictions. Legalization would merely be official acknowledgement of the sympathetic attitudes toward mercy-killers that already exist in the courtroom.

6. A majority of the public, in repeated annual polls and in increasing numbers, supports the view that there are circumstances under which a doctor should be legally permitted to grant a patient's request for a lethal injection. The polls appear to reflect the view that, given a choice between dying a slow, agonizing death or a peaceful, painless death from a fatal injection, very few of us would choose to suffer. If we would not want such a death forced upon ourselves, we should not require others to live by a law that dictates their choice by prohibiting active euthanasia.

7. Under certain circumstances, active euthanasia promotes everyone's best interest. In these cases, euthanasia serves to eliminate the patient's suffering, to lessen the family's emotional and financial burdens, and to release medical resources for patients who can be helped. When a social policy benefits everyone and at the same time violates no one's rights, it should be permitted under the law.

8. The benefits and burdens of active euthanasia should be evaluated in the same way as other medical procedures. Sometimes treatment is futile to the point where even providing food and water presents a monumental task. Feeding the patient is possible by inserting tubes through the nose to the stomach or intravenously through one of the

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major veins in the chest. The latter is more traumatic and increases chances of blood-clotting, infection, hemorrhage, malnutrition, or other complications that cause suffering and death. When we know that treatment is futile and will involve burdens to the patient that cannot be outweighed by the benefits, to require that the patient be subjected to slow death by starvation as the alternative is inhuman. We must allow the option of aiding patients in dying quickly and painlessly. Aiding in death by providing a lethal injection wouldn't be any worse than causing death by starvation and dehydration. In neither case would death be a result of a pre-existing condition. Take, for example, the case of Elizabeth Bouvia. Bouvia, who was not terminally ill, was bedridden, quadriplegic, and in a state of chronic pain. In 1983 she attempted to starve herself, and then was force-fed by a nasogastric tube in spite of her refusal. One of the judges in her case (speaking for the court of appeals that eventually ordered the feeding tube removed) said, "The state and the medical profession, instead of frustrating desires, should be attempting to relieve suffering by permitting and, in fact, assisting death with ease and dignity. The fact that people are forced to suffer the ordeal of self-starvation to achieve their objectives is inhumane. The right to die should include the right to enlist assistance from others, including physicians, in making death as quick and as painless as possible."

9. A person's desire to end his or her own life is a personal matter between the patient and the physician, who acts as the patient's agent. The state has no right to interfere with another's choice in this case, even if in doing so the law is enacted for the person's own good. Our society places an extremely high value on self-determination. Though most dying patients can have their pain managed effectively, the prohibition

against active euthanasia and assisted suicide results in denial of self-determination for many. Our moral and legal traditions have always placed a high value on self-determination. The law should protect us against loss of liberty with respect to personal choices.

Position 2 – Legal status should be given to Living Wills and other advance directives that would allow people to die a natural death with dignity, but mercy killing and assisted suicide should be legally prohibited under all circumstances.

The right to die with dignity does not include the right to be killed or to be assisted in suicide when one no longer considers life worth living. Rather, it is the right to refuse treatment when the burdens of medical intervention outweigh the benefits. Advances in medical technology have enabled doctors to keep people's bodies functioning indefinitely. However tempting it may be, this ability should not lead us to engage in a relentless pursuit to extend life. We must acknowledge that while new technology is often able to save the lives of people who would otherwise have died, saving these individuals often consigns them to an existence of chronic and debilitating illness. Extending life should have its limits.

Limits on the benefits of life-prolonging technology. There are thousands of comatose patients connected to feeding tubes. For many in this situation there is no real hope of regaining consciousness. Furthermore, in some cases their organs have deteriorated to a point at which they could not survive for any length of time even if they were to regain consciousness. These patients should be allowed to die with dignity. In addition, there are many other individuals who have very rich mental lives but who are living with conditions (terminal illness, chronic debilitating illness, or severe handicaps) that make it impossible for them to function on their own. They often consider the benefits of continuous medical intervention to be outweighed by the physical suffering and mental anguish produced by the invasive procedures necessary to keep them alive. We should not permit humane, family-centered medicine to be completely replaced by an intrusive technological science.

Legal allowances. From this perspective, all states should give legal status to Living

Wills and other advance directives. This would allow individuals who can no longer speak for themselves or whose competency is questionable the right to demand that their lives not be artificially prolonged if they become terminally ill or irreversibly comatose. It would also make provisions for the right to refuse any form of treatment if the benefits of the treatment could no longer counterbalance the burdens. Instead of being used merely as suggested guidelines for physicians, providing legal status in every state would better ensure that patients' wishes are carried out.

Legal prohibitions. However, while we must guarantee the right of citizens to have control over their own dying processes, a legal policy allowing for active euthanasia and assisted suicide would signal that our society places very little value on human life. This prospect would have grave social consequences. Condoning voluntary euthanasia is likely to lead to the killing of others whom we regard as failing to possess a life worth living. Consider, for instance, severely deformed infants, the irreversibly comatose, the handicapped, the mentally impaired, and others who cannot speak for themselves. Once we have adopted a policy that allows for the direct, intentional killing of some innocent persons, what logical and moral considerations could be offered that would prevent us from legalizing the killing of others who may be a financial liability to society and who are living the kinds of lives people consistently say they would not consider worth living? There is no adequate means of safeguarding against abuses that would move us from a policy of voluntary active euthanasia and assisted suicide toward a policy allowing for mercy killing of anyone society considers an unworthy burden. Remember, there is a short and easy slide down the

slippery slope toward the "euthanasia" policy adopted by Nazi Germany. What started out with a few doctors acting in the name of mercy ended up as the illegitimate and malevolent use of nonvoluntary and involuntary euthanasia primarily for the supposed benefit of certain segments of society. Thus, we should vigorously oppose any policy that either decriminalizes or makes explicit legal sanctions permitting active euthanasia and assisted suicide in any form.

Problems with assuring voluntariness.

Finally, even if we could be certain that a policy of voluntary active euthanasia would not have disastrous social consequences, such a policy would be impossible to implement. By adopting a paternalistic stance in order to protect against violations of individual rights, both the state and physicians must evaluate decisions made by patients under their protection and care. It is not always clear when a person's decision to end his or her own life is a free and rational one. A patient who is terminally ill, in constant pain, chronically ill, or physically disabled to the point of being unable to live under his or her own power is bound to be depressed. The desire to cease being a burden on others and to gain at least temporary relief from the anguish or humility of daily living may prompt a request for death. Hoping to spare their loved ones the pain of seeing them endure a prolonged dying process and anxious to relieve their relatives of further financial burdens, some may ask to die only out of concern for the well-being of others. Allowing people to have their lives actively ended will only foster the perception, often motivated by prejudice, that certain lives are not worth living. The result would be increased pressures to ask to be killed even if the patient doesn't consider life excessively burdensome for himself or herself.

Underlying Principles and Assumptions

1. Once the respect for human life is so low that an innocent person may be killed directly, even at his or her own request, compulsory euthanasia will soon follow. Just look at the example of Nazi Germany. Millions were "euthanized" because of their presumed racial, ethnic, mental, or physical inferiority. Mass genocide began with a group of German doctors believing that some lives were not worth living and that those who had to live them would be better off dead. Once one kind of killing is rationalized we have stepped onto dangerous ground, where there are no arguments for excluding other forms of euthanasia. For this reason, active euthanasia under any circumstances must be condemned.

2. Those who advocate voluntary active euthanasia must acknowledge the very serious potential for abuse in its application. Many people who are burdened by their ailing relatives would attempt to describe acts of cold-blooded murder as acts of compassion. Even if active euthanasia were morally permissible in certain cases, we must guard against its legalization because it would be almost impossible to ensure its just application.

3. The elderly and infirm in our society have every right to expect to be cared for by others when they can no longer care for themselves. If we do not rigorously oppose legalization of active euthanasia, it might come to be expected that one who will need long-term care or a great deal of expensive care should call for the doctor and demand death. Legalized active euthanasia would make all of our lives less secure. The right to die should not be replaced by a duty to die.

4. Keeping people's bodies functioning on machines often represents the ultimate misuse of technology. Technology now permits us to maintain physiological life long

past the point when a human being possesses those characteristics essential to being a person — namely, a conscious life consisting of self-awareness, rationality, thoughts, feelings, and desires. The person has ceased to exist. It is a violation of the right to die with dignity to keep the person's body alive using artificial means.

5. Underlying all of the moral principles within the norms of practice adopted by physicians is the principle of respect for life. This is significant since more than 80% of Americans die in hospitals. The Hippocratic oath, developed by the Greek physician Hippocrates in ancient times and still taken by doctors, includes the pledge, "If any shall ask of me a drug to produce death I will not give it, nor will I suggest such counsel." Therefore, active voluntary euthanasia is contrary to one of the basic tenets of the medical community. A policy allowing physicians to perform active euthanasia would severely undermine the trust that must be at the basis of a good doctor-patient relationship.

6. There is a moral consideration supporting a law that permits letting some patients die a natural death while it prohibits the humanitarian killing of patients. Consider patients who have been wrongly diagnosed as hopeless: some of them will be able to survive even when treatment is ceased in order to allow a natural death. Others will be able to survive only if treatment is continued. Allowing patients to die will lead only to preventable deaths of people in the second category, whereas permitting active euthanasia will also lead to some preventable deaths of members in the first category. Allowing active euthanasia under the law will therefore lead to the deaths of some who could otherwise have been saved.

7. The dying more often feel in need of comfort than of treatment, and can best judge their own interests and needs. The patient's interests and desires are the most

important in the process of deciding whether to provide life-saving treatment. According to the law, even when a patient is incompetent the surrogate should take into account knowledge of the patient's feelings and desires before incompetence.

8. The right to refuse treatment is basic and fundamental, as a part of the right to privacy. On the same ground, the right to refuse treatment is accompanied by the right to have treatment discontinued.

9. Some patients have permanently lost consciousness and cannot benefit from having their lives sustained. Withholding treatment in these cases violates neither obligations to society nor the individual. The duty to preserve life should not be interpreted as the duty to preserve every life at all costs.

10. There is an important moral difference between administering pain medication in order to lessen suffering, with the knowledge that the cost may be the hastening of the patient's death, and killing a patient in order to end the suffering. In each case the patient's death is brought about sooner than it would have occurred otherwise. But, in the first case, the patient's death is a foreseen but unintended consequence of pain relief. In the second case, however, the patient's death is clearly intended as a means to the end of halting the suffering. While the second is morally forbidden, the first is not.

Position 3 – Both mercy killing and allowing patients to die by withholding life-saving treatment should be legally prohibited, even when requested by those who are competent and terminally ill.

All human life is precious and should be preserved at all costs. Life should be cherished despite disabilities and handicaps. We live in a society that values beauty, youth, fitness, and power; it is no wonder that people without these would regard their lives as no longer worth living. These social prejudices along with the lack of financial aid and counseling for many terminally-ill and severely handicapped patients would understandably lead them to consider requesting death. Instead of continuing to abandon these individuals by giving them permission to die, we should make an effort to create a caring and supportive community for them during the time they have left. In this context, perhaps they would view their lives as valuable.

The potential benefits of life-sustaining technologies. Respect for a person's autonomy should not be allowed to take precedence over respect for life. Many doctors and patients mistakenly believe that when there is a great deal of uncertainty with respect to the value of a given treatment that it is somehow better not to initiate the treatment than to start it and have it withdrawn. The result is that patients who fear life-long dependency on machines refuse treatment with the consensus of the physicians. The effect is the denying of life-sustaining treatment to some patients who could have been benefitted. Doctors, patients, and their families should be much more willing to try therapies such as ventilator support.

Refusing treatment vs. suicide. Further, the foregoing of life-support in many cases is simply another form of suicide or assisted suicide. The courts have attempted to distinguish refusal of life-sustaining treatment from suicide by arguing that in foregoing treatment the disease, as opposed to a self-inflicted injury, is the cause of death. How-

ever, even though the courts may point to a legal distinction, there is not always a moral distinction. Decisions to commit suicide made by competent adults usually involve a judgment along the following lines: "The best conditions I can hope to live under in the future are so bad that it would be better to have no life at all." But this is exactly the same sort of judgment made by many of those who decide to forego treatment. Their refusal of treatment is the means they use to end their lives when conditions become so bad that life is no longer considered worth living. They would not have died now except for their refusal of treatment. Just as those with terminal diseases can end their lives by taking an overdose of medicine, they can also commit suicide by not allowing someone to save them. While we should respect the freedom of others, no one has the right to use that freedom against himself or herself by destroying human life, even if it is one's own.

The changing definition of "extraordinary treatment." We are already on the slippery slope toward mass murder that people fear. Only a few years ago food and water were considered basic necessities of life to which everyone had a right. Now, the medical and legal communities have arrived at a point at which even nutrition and hydration are considered forms of extraordinary treatment that can be removed upon request. Allowing people to exercise what they consider to be the right to die with dignity by refusing "heroic measures" has led to some very gruesome, undignified deaths. Unless we value all life, regardless of the conditions under which it is lived, we will continue our slide into barbarism.

The obligation to sustain life if at all possible. Though it may seem even more

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cruel to suggest that there is a duty to live no matter what the quality of one's life, everything in life has a purpose. Suffering may seem pointless and is certainly difficult to endure, but we shouldn't give in to the temptation to end life when it can still be preserved. Life should be maintained regardless of the cost, the person's physical condition, or the chances of recovery. A dying person, after all, is still alive. And where there is life, there is hope. We have all heard stories of "terminally ill" patients who have miraculously recovered, despite the most discouraging prognoses. This demonstrates that it is not for individuals or their physicians to decide when a person shall live and when a person shall die. Doctors have no right to play God with people's lives.

Underlying Principles and Assumptions

1. The sanctity of life is not overridden by a person's suffering, indignity, or even a person's own wishes. Life is intrinsically valuable. Any intentional taking of human life violates the person's right to life, even if the person no longer considers life worth living.

2. Doctors have no right to play God with their patients' lives by deciding who will be allowed to live and who must die.

3. Doctors have sometimes been mistaken in declaring a person terminally ill or irreversibly comatose and claiming that there is no hope of a recovery. To have allowed these patients to die by removing them from life-support systems or to have killed them because their condition was "hopeless" would have meant a tragic shortening of meaningful lives. We can never be certain that a patient will not recover. Therefore, we must do whatever we can to preserve that possibility.

4. Allowing people to suffer may seem like an evil that could never be justified, but tragedy often brings out the best in people. Those who are suffering can serve as examples of courage. Those who are witnesses to

the suffering are many times moved to great acts of charity and kindness.

5. Death is a worse evil than suffering.

6. Many patients who have signed Living Wills did not get the natural, dignified deaths they were looking for. Patients don't understand that exercising the right to refuse treatment often condemns them to death by dehydration, vomiting, organ failure, and suffocation. These are not easy deaths that allow one to "go gently into that dark night."

7. In many cases, there is no distinction between refusing life-saving treatment and suicide or assisted suicide.

8. Mercy killing and allowing people to die when their lives could be prolonged will lead to the erosion of resources directed at cures.

9. The state plays the role of *parens patriae*, through which it serves as guardian to the young, retarded, indigent, incompetent, and others who cannot defend their rights. In this role, the state should dictate that if the courts and medical community are in a position to err with respect to the best interest of patients, then it must be on the side of life.

Glossary

Advance medical directive. A document produced by a **competent** individual that is specifically addressed to the person's physician or that appoints a legally designated agent for health care matters. This document specifies the person's desires regarding medical treatment if he or she were ever incompetent and unable to speak for himself or herself.

Autonomy. The concept that holds that a **competent** patient is entitled to decide whether to be a patient and to make important decisions about treatment.

Beneficence. Acting to benefit patients by sustaining life; treating illness. Health care providers are to pursue only treatment that contributes to the well-being of their patients. The principle of beneficence states that the physician has a legal obligation and a moral duty to use only those treatments that would benefit the patient. If a particular medical intervention, such as resuscitation, is not in the patient's best interest, the physician is morally free (and may be morally obligated) to withhold or withdraw medical intervention.

Best interest. If the incompetent patient has never been **competent**, or if the patient was once competent but never expressed wishes about terminal care, it is meaningless to speak of extended **autonomy**. In these cases it is recognized that a surrogate ought to attempt to serve the best interest of the incompetent. The courts do not normally permit **substituted judgment** when there is no information about the patient's preference. Only the best interest standard may be applied.

Chronic pain. Pain over a long time span, usually of an incurable, underlying cause.

Coma. An acute loss of consciousness that usually consists of a sleep-like state from which a person cannot be roused that may be followed by varying degrees of recovery or that may result in severe, chronic, neurological impairment. See also **persistent vegetative state**.

Competent. Capable of making decisions on one's own behalf. *Competency* allows a patient the right to forego treatment even when the medical profession or society would judge the decision and reasons for the decision irrational.

Durable Power of Attorney for Health Care. A legal document that names an agent who will make health decisions on the part of an individual who becomes unable to express wishes for himself or herself.

Informed consent. Common law dictates that before any person may touch another person's body, he or she must have consent to do so. This principle, which is related to the right of privacy and the right to prevent the invasion of privacy, is applicable to the physician-patient relationship since treatment of a patient usually involves touching.

Living Will. A document produced by a **competent** individual stating his or her wishes regarding medical care if he or she were to become incompetent and unable to express his or her desires for health care.

Persistent vegetative state. A chronic state of unconsciousness caused by overwhelming damage to the brain. The body continues to awaken and sleep cyclically, but there is no cognitive function or ability to respond in a learned manner to external events or stimuli.

Substituted judgment. A legal standard in which a patient's surrogate attempts to make the health care decisions that the patient would make if the patient were competent. Substituted judgment is based on a patient's own values as best as can be determined and may differ from **best interest**.

[These terms and definitions are excerpted from a more extensive glossary in: David E. Outerbridge and Alan R. Hersh, M.D., *Easing the Passage: A Guide for Prearranging and Ensuring a Pain-Free and Tranquil Death via a Living Will, Personal Medical Mandate, and Other Medical, Legal, and Ethical Resources* (New York, NY: HarperCollins Publishers, 1991), pp. 141-146.]

THE STYLE

LAST RIGHTS



in sickness and in health, more people are taking life's biggest decision away from doctors and into their own hands

Marie was dying. Her 69-year-old body, wasted by incurable emphysema and inoperable lung cancer, could no longer function on its own. As her family stood by her hospital bedside on a hot summer morning, the doctor suggested hooking her up to life-sustaining equipment. Marie looked beseechingly at her daughter Rose. "What do you think?" she asked. "No, Mom," Rose answered. Marie nodded. The doctor bristled. "If that were my mother, I'd do it," he said. But the family stood firm. The following day Marie died quietly, without the whirs, clicks and high-tech hums that form an electronic dirge for so many Americans. Last week Rose explained why she was buying "Final Exit," Derek Humphry's controversial new best-selling guide to suicide. "I don't want what happened to me to happen to my children, to have a doctor try to dictate to them," she said. "It's an outrage. When I'm dying, I want to be in control."

Whose death is it anyway? More and more people—whether they are terminally ill, know someone who is, or are simply confronting their own mortality—are asking that question. To die in America is no longer simple. Before the 1950s, most patients died at home. Now they may spend their final days (or months or years) in a hospital or nursing home, often attached to sophisticated machinery that can extend even the most fragile life. "Doctors have always been in control,

but now it's not just doctors and patients," Ruth Macklin, professor of bioethics at Albert Einstein College of Medicine in New York City, says. "There are hospital administrators, in-house attorneys and risk managers... These are the people who are *really* in control." To circumvent that tangled bureaucracy, to avoid the crushing burden of extended illness, many people now consider the possibility of taking life—and death—into their own hands.

Bookstores can't keep "Final Exit" in stock; almost 150,000 copies of the slim, \$16.95 volume are on order. Before "right to die" entered the lexicon, before Karen Anne Quinlan, Nancy



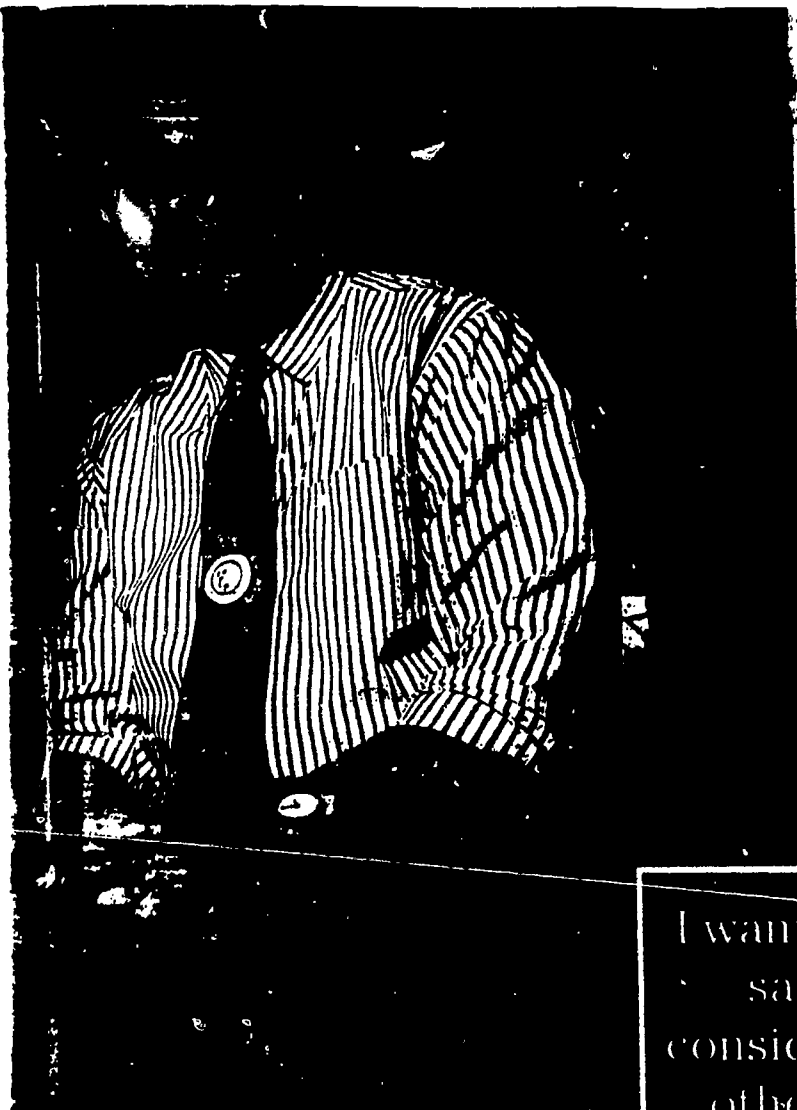
WILL TYNAN

Quill explores boundaries



DEAD MARCH—BAMBA-LIAMON

Cruzan's family at the Supreme Court



ROBERT McCLARAN

Cruzan and Dr. Jack Kevorkian became familiar names, "Final Exit" would have been unimaginable. Only 41 percent of the respondents in a 1975 Gallup poll said they believed that someone in great pain, with "no hope of improvement," had the moral right to commit suicide. By 1990, that figure had risen to 66 percent. Derek Humphry, president of The Hemlock Society, a euthanasia organization founded in 1980, thought the time was right for a "responsible" suicide manual. Though "Final Exit" is straightforward, it is not an emotionless directive. "I wanted it to say, 'Be considerate of others, go careful with your life and other people's feelings,'" Humphry says. A man whose ailing, elderly parents committed suicide after reading "Final Exit" wrote to Humphry: "For what it is worth, we thank you for providing accurate information and advice."

Though "Final Exit" proposes an extreme measure for ending life, it speaks to a growing concern of most Americans. With continuing advances in medical technology, the prospect of being kept alive—perhaps insentient—by machinery is real and frightening. About 1.3 million Americans die annually in hospitals, hundreds of thousands more in nursing homes; many end their lives with a negotiated death (page 42). More and more people are asking what they can and should do now to try to ensure a dignified, humane death. There are several documents which can help, but the laws governing them are patchwork. Speak to a lawyer, a doctor and your family.

■ **Living Will** outlines what medical treatment you want—or do

not want—should you no longer be able to express your wishes. Its legal limits vary; fill in one for the state in which you live.

■ **Health-Care Proxy** designates an agent—a friend or family member—to act for you in health-care matters. It is often included within a living will and, like it, may have limited powers. For example, it may cover only terminal illness, which would not include a coma or Alzheimer's disease.

■ **Durable Power of Attorney for Health Care**: a more inclusive document that permits your agent to act for you in most health-care matters, including those you might not have considered.

Most Americans—84 percent, according to a 1990 Gallup poll—say that if they were on life-support systems and had no hope of recovering, they would want treatment withheld. Like diabetics or heart patients, they can purchase Medic Alert bracelets, but theirs are emblazoned **LIVING WILL/DO NOT RESUSCITATE**. "There has been an extraordinary decline in trust between physicians and patients, and patients and hospitals," says David Rothman, author of "Strangers at the Bedside" and professor of social medicine at Manhattan's Columbia College of Physicians and Surgeons. "People don't believe that the hospital will do what they want."

Under the full glare of the media, courts and medical journals are debating right-to-die decisions. Says Dr. Robert McAfee, a Portland, Maine, surgeon and vice chairman of the American Medical Association's board of trustees, "Our social contract is to sustain life and relieve suffering. But sometimes

these ideals are in conflict." They were for Dr. Timothy Quill, an internist in Rochester, N.Y. Last March, in *The New England Journal of Medicine*, he wrote movingly of how he helped a leukemia patient stockpile barbiturates so she could take her own life: "I [had] an uneasy feeling about the boundaries I was exploring—spiritual, legal, professional and personal. Yet I also felt strongly that I was setting her free to get the most out of the time she had left, and to maintain dignity and control on her own terms." Last month a Rochester grand jury refused to indict Quill on criminal charges, including manslaughter. Still, some worry that patients may not make informed choices about when and how to die. "I feel a great deal of discomfort about how comfortable people have become with [euthanasia]," says Carol Gill, director of psychological research at the Chicago Institute of Disability Research. "I take a very suspicious view of 'voluntariness' in these issues."

We may never be able to codify the complex ethics of medical technology. There are, however, changes afoot. A new federal law, the Patient Self-Determination Act of 1990, goes into effect this December: it will require hospitals participating in Medicare or Medicaid to ask all adult inpatients if they have "advance directives" such as living wills. In Washington state, legalized euthanasia is a possibility. The November ballot will carry an initiative with an "aid in dying" provision that would allow doctors to help the mentally competent, terminally ill die. Patients could request help in writing at the time they want to die. Two witnesses would have to certify that the request is voluntary.

Most of us have some choice in how we live, certainly in how we conduct our lives. How we die is an equally personal choice—and, in the exhilarating and terrifying new world of medical technology—perhaps almost as important.

KATHINE AMES with LARRY WILSON and RAY SAWHILL
in New York, DANIEL GLICK in Washington,
PATRICIA KING in San Francisco and bureau reports

I wanted it to
say, be
considerate of
others. Go
careful with
your life, and
people's
feelings.

CHOOSING DEATH

**In three weeks in a Boston hospital's
intensive-care unit, three families struggle
with the meaning of loving enough to let go**

Domenic Ponzo's final journey began at 3 a.m. one day last May, when he awakened at his East Boston home with a sharp pain in his side. His visit to the local health clinic turned up a serious gallbladder problem, and soon after Ponzo found himself in one of the 12 private rooms at the Medical Intensive Care Unit (MICU) at Boston's Beth Israel Hospital. His gangrenous gallbladder had been removed, his kidneys had

completely collapsed, his lungs were laboring to inflate on their own, his heart was weakened by a coronary during or soon after the gallbladder surgery.

It all happened with such numbing swiftness. Just two weeks after his predawn agony, Ponzo's medical options were dwindling. As his hope for life faded, replacing it was not the peaceful certainty of death but the terrifying unknown of dying. His body could not tolerate more surgery. Although poisonous wastes were building up in his system, dialysis had to be halted because it triggered his angina. He was slipping in and out of consciousness; soon his lungs would be no more able to gather in oxygen than a punctured balloon. Ponzo's wife of 31 years was summoned to a tiny "family room" outside the MICU, where three doctors and a nurse waited for her. "Is he dying?" asked Adeline Ponzo, 67, as soon as they sat down. "It looks pretty grim," replied Dr. Joel Snider, Ponzo's personal physician. For the next 20 minutes, the doctors delivered the same fundamental message in many different ways: without massive and heroic intervention, her husband would almost certainly die within 48 hours. They counseled her not to request any extraordinary measures that, as they put it, would only prolong his misery. Grasping for the ungraspable, Mrs. Ponzo asked, "Do you mean just let him go?"

The doctors explained that there were no reasonable medical options. A ventilator to breathe for him, drugs to support his blood pressure, electric shocks to jump-start his sputtering heart might keep him alive for another week or so. But to what end? The best course, they said, was to keep him comfortable and permit him a peaceful, dignified death. "We'll do everything short of 'everything,'" promised Dr. Scott Weiss, a pulmonary specialist and the attending physician on the MICU that month. Weiss, whose candor and forcefulness at times make him appear brusque, assured her that it was the right decision. "It may be for you, doctor," Mrs. Ponzo said softly, more in sorrow than in anger. "But he's all I have."

Early the next morning, the cloud seemed to lift from Ponzo's mind, and for a brief few moments he saw his wife, and perhaps his end, with a calm lucidity. They exchanged final "I love yous." "I just held him in my arms," Mrs. Ponzo said. "I took off his [oxygen] mask—he didn't need it anymore—and held him and held him until his final breath."

It was a good way to die, as dying goes, for sometimes it goes

I have decided
to end my
life as I do not
want to live
like this. I
don't want to
make a big
deal of this.

PHOTOS BY IRA WYMAN FOR NEWSWEEK

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Do you mean
just let him
go? It may be
[the right
decision] for
you, doctor.
But he's all
I have.

horribly. "A peaceful death," Weiss said softly as he led interns and residents past Ponzio's closed door on morning rounds a few hours later. It could even be counted a sort of success. Ponzio did not suffer the outrage of "people sticking needles in [him] and thumping on [his] chest. That's a violent and brutal way to depart this world," said Weiss to the interns and residents gathered around, and to a reporter who would spend 21 straight days in the unit, seeing and hearing how doctors, nurses, patients and relatives wrestle with the siren of high-technology medicine that offers both hope and peril. If there is a philosophy that unites Beth Israel's staff, it is that just as tubal feeding, or surgery, or a ventilator is a medical option, so is death. "You have a responsibility not to drag out the dying," says Weiss. "I don't believe in euthanasia. But I don't think we're here to do things that are inappropriate. Some doctors think that once you invoke the high tech, you can't get off the train. But you ought to be able to opt out."

The option that more and more patients, and their families, demand is to leapfrog dying if death is all that awaits. While many people choose death, no one chooses dying. Although there are no national statistics, anecdotal evidence suggests that more than half of hospital deaths follow a decision to limit or withhold life-sustaining treatment. This is not suicide, or euthanasia, for both of those mean ending life. It is, rather, a desire to end dying, to pass gently into the night without tubes running down the nose and a ventilator insistently inflating lungs that have grown weary from the insult.

Not so often the life leaves few clues to how the dying should come. The Ponzios had never discussed what to do in such a situation, even though Domenic had a history of diabetes, chronic pulmonary disease, high cholesterol, obesity, peripheral vascular disease, hypertension, high blood pressure and angina. A pack-and-a-half-a-day smoker for 50 years, Ponzio, 69, experienced shortness of breath after walking a single block. Adeline Ponzio, who had worked as a medical assistant for the past 15 years, would sometimes raise the subject of death and dying, but her husband would shush her. "If I brought up anything to do with it, he'd just say, 'I don't want to discuss it.' He's not a weak-type person, but he just couldn't discuss this type of thing."

But there is a danger in not discussing. If the patient and family do not clearly state their preference, doctors are obliged by Hippocratic oath to err on the side of intervention. One distinguished physician who became a patient in the unit requested they do "everything possible"—except snake tubes down his throat and into his veins. Since "everything possible" includes intubation almost by definition, the MICU staff followed his first request without caveat. He died two weeks later. Tubes stuck out of every orifice of his body.

Experiences like that push the MICU staff to help family members reach the most difficult decision they will ever face. Their mandate is to spare the relatives the sense that they bear the entire burden of the decision and its outcome. "It's important not to say, 'What do you want?'" says Weiss. "It's not fair. Deciding is a heavy burden to lay on someone," and one that even professionals for whom death is an intimate acquaintance have trouble shouldering.

Sometimes the staff gets lucky, as luck is measured in the MICU. Sometimes they have an exceptional case, in which a fully alert patient questions a prolonged dying. Helen Reynolds, 63, had undergone operations in January and April to repair and then replace a heart valve that was not permitting a smooth flow of blood. But by May her feet had turned the color of overripe eggplants, their mottled purple black an unmistakable sign of gangrene. The consensus was that, at best, she would emerge from Beth Israel's MICU a "pulmonary cripple," almost surely sentenced to live out the rest of her life in a chronic-care facility, perhaps forever yoked to a ventilator. But Reynolds had no intention of giving up. Leashed to the softly whooshing ventilator, she was prepared to offer her very flesh if that would appease Thanatos. In June she chose to have first her right leg, and then her left, amputated in hopes of stabilizing her condition. The doctors were skeptical about the surgery, but deferred to her wishes.

The gutsy decision was very much in character. Reynolds's first husband had committed suicide by strangling himself in 1971. To support two teenage daughters still living at home and to hold onto her home in Norfolk, Mass., she worked three jobs: in a paint shop at a Corning Glass Works plant and waitressing at two local restaurants. She had to stop working when her heart problems began, in 1978. Between the first and second

heart operations, she lived in a rehabilitation hospital, oxygen tank beside her and, despite chronic breathing problems, cheerily chatted with her visiting daughters and 83-year-old mother until long after she should have been resting.

Even when the April heart operation at Beth Israel forced her onto a ventilator, she never withdrew from what her life had become. She delighted in the MICU nurses doing her hair and makeup. When doctors turned down her television so they could talk during their morning rounds to her room, she gestured for it to be turned back up immediately after they left. In May she and her family celebrated her 63rd birthday, with balloons, flowers and a two-foot-tall **HAPPY BIRTHDAY FROM ALL OF US** card, there on the ninth-floor MICU with its picture-window view of Boston's western suburbs. She occasionally watched videos that the MICU nurses brought in. It was during one incongruous double feature—the elegant "Room with a View" and the teen dance flick "Shag"—that nurse Ruth Scanlan told her, "Helen, it really stinks. You know if you don't want all this stuff done, we can stop it. We can let nature take its course." Reynolds shook her off. She knows what I mean, Scanlan thought. She wants to live. Asked how she so stoically weathered every indignity done to her, Reynolds replied simply, "I want to get home."

But then Reynolds uncharacteristically began talking about her pain. On that Sunday afternoon in June, a nurse beckoned intern Dr. Randall Evans. Evans, a graduate of the University of New Mexico Medical School who planned a career in the critical-care field, was immensely popular with the nursing staff for his cordial and sympathetic manner. But, unlike the MICU nurses, he had difficulty reading Reynolds's lips (the ventilator made it impossible for her to speak aloud), and asked her to write down her request. Laboriously, she scrawled 16 words on the note pad: "I have decided to end my life as I do not want to live like this."

Evans asked her if she knew what her decision meant. She pointed to her head to indicate she wasn't crazy. Asked if she might change her mind, she shook her head vehemently. As Evans prepared to leave, Reynolds mouthed a final wish: "I don't want to make a big deal out of this."

Reynolds broke the news to her daughters. Maureen Labrie emerged from the room in tears. "I was surprised she stuck it out so long," she said. "I think she hung on more for us than herself."

Gayle MacPherson, her eldest daughter, listened and asked if she wanted to see a priest. Reynolds, apparently afraid that the priest

would try to change her mind, declined firmly. "I'm not trying to talk you out of it," Gayle assured her. "It's been your decision all down the line. Whatever you decide is OK. That doesn't mean we won't be sad, but it's OK. I don't want you to have that anxiety of worrying about if we're going to be upset with you. I don't blame you." Asked the next morning how it had gone with her daughters, Reynolds mouthed, "Not too well."

Yet her daughters had expected the decision weeks before. When Reynolds chose to have her second leg amputated, Gayle recalls, "I thought at this point she would say, 'Enough already, I'm tired.' I wouldn't blame her. I'm tired too. But if she wants the surgery, that's fine. We'll support whatever she wants."

The doctors understood Reynolds's decision, but they could not grant her wish right away. "We're going to string this out a couple of days," intern Evans told the medical team. "I want her to tell me the same thing many days in a row." Explained Dr. J. Woodrow Weiss, director of the MICU, "We need to be certain this isn't a whim." Reynolds did reiterate her decision—countless times—to Evans, to Weiss, to her family and to psychiatrist Eran Metzger. It was his task to determine whether Reynolds was competent and whether her decision was based on "appropriate" rather than "inappropriate" depression.

On Thursday evening, Woody Weiss, Evans, Metzger and Reynolds's primary nurse Judith Ayotte met with her three daughters, mother and a granddaughter. "What she has told us basically is that she doesn't want to be kept alive, that she doesn't want to continue going through all that she's gone through," said Weiss. "Our feeling both ethically and legally is that we should respect her wishes." The best way was to remove her from the ventilator, lines and tubes. The principal concern was pain and discomfort. "She told me she'd just like to go to sleep," Gayle said. "She's tired. She's had it." The doctors said they would give her mother morphine for pain. The only question left was when to remove the ventilator. Reynolds rejected out of hand her family's suggestion that she might like a few more days to say her goodbyes. Her patience and endurance were at an end. She was ready.

"I want you to know I admire you a great deal," Evans told

It's important not to go in there and say, "What do you want?" Deciding is a heavy burden to lay on someone.



her as he prepared to remove the ventilator on June 20, four days after her imploring note to him. "We're going to help you do what you want." "Thanks for listening to me," Reynolds whispered. The family gathered round. "Life won't be the same without you," her mother said. In a few hours Reynolds drifted off to sleep, breathing easily. Her family headed home.

Reynolds was undoubtedly the most surprised and unhappy person of all when she awoke the next morning. She managed a laugh at the bitter irony, and clung to life for another three days. She died early on Monday, June 24. It had taken a little more than a week for her wish to be granted.

The hovering presence of death breeds a steely attitude on the MICU. Nurses and doctors regularly declare that they want "DNR" (Do Not Resuscitate) incised on his or her chest. "But until it's you or yours," says Miriam Greenspan, chief nurse, "I'm not sure you really know."

Even patients, or families, who think they know often do not. The most common shock is finding out that not deciding is, in fact, deciding: if a family or patient does not refuse a respirator, feeding tube or other life-sustaining measure, the doctors can not and do not withhold it. And few people are prepared for what follows. "Too often," says Greenspan, "it's only after we've [started life support] that the family truly understands and says, 'Oh my god! That's what "do everything" meant.'" That's why the MICU staff regards "living wills" as less than perfect: these documents stipulate what a patient will and will not want, but they cannot anticipate the grim complexities of disease. Perhaps a despised ventilator will be needed for only a few days, perhaps tubes for only a few hours. It may be better to designate a health proxy, someone who understands the patient's attitudes toward dying. The proxy is charged with making medical decisions when the patient cannot, and can weigh the specific circumstances of the illness and the choices available. The proxy's legal standing varies from state to state. But designating one may avoid the added tragedy of deathbed fights. Says Weiss: "The daughter who's been visiting the father every day for years might say, 'I want to do what's best for him.' The son who hasn't visited in five years flies in and says, 'I'm not going to let you kill my daddy!'"

Sometimes the doctors themselves do not know—not about whether death will come, but when. Richard (not his real name) certainly seemed to have almost no time left when he returned to Beth Israel in June for the 41st time since March 1988. An alcoholic, Richard suffered from cirrhosis of the liver and its consequence, esophageal varices. In this condition, blood is unable to flow through the liver and detours in excessive quantities through the esophagus. There, blood vessels and veins unable to handle such a flow continually rupture.

That's why Richard kept showing up at Beth Israel. He had received enough transfusions to refill a man 18 times. He had also received the standard treatment for varices: a tube down the esophagus releases an agent that stops the bleeding. When his throat could not tolerate the tube, Richard began receiving intravenous pitressin, a drug that reduces the flow of blood to the overtaxed esophagus. Then he would go home until the next rupture.

Their recidivist patient was amiable enough—soft spoken, a man who loved his dog and his flower garden behind his home a short distance from Beth Israel. He lived with a roommate, who

visited Richard faithfully during his stays at Beth Israel. At the MICU Richard relished his favorite lunch—mounds of vanilla Häagen-Dazs washed down with ginger ale. He said he'd stopped drinking a few months before, but still the staff found it hard not to view the fortyish lab technician as a victim of himself. In a prominent big-city teaching hospital like Beth Israel, medical care is plentiful; it's sympathy that has to be rationed.

Now medicine could not offer much, either. Gastroenterology fellow Dr. Deborah Proctor broke the news to Richard on a glorious Friday afternoon, as sunbeams danced on the off-white linoleum floor. They had run out of options, she said. Surgery to insert a shunt in his liver to carry blood through was out of the question; the cirrhosis had so debilitated him that he would likely die on the operating table. He had earlier tested positive for HIV, which causes AIDS; that made him a poor candidate for surgery. "Richard, there are no options for you left," Proctor told him. "We can't keep pouring blood into you. You're going to die."

His face betrayed no emotion. "If that's what's going to happen, that's what's going to happen," he finally answered. Proctor said she needed his consent for a DNR order. He agreed.

She asked if he accepted that there would be no more transfusions or pitressin. If his esophageal veins ruptured again, the staff would not staunch the bleeding. He would quickly lose consciousness. He would bleed to death.

Richard understood. He acquiesced.

"I do mind dying," Richard said soon after his talk with Proctor. "But I haven't any choice. They explained it all to me, and there wasn't any other decision they could make. My life has come to a point where it can no longer succeed." The doctors, too, emphasized the uselessness of it all. "It's a question of futility," said MICU resident Dr. Ira Oliff. "We don't keep corpses on ventilators either." Scott Weiss agreed: "He's had a good run for his money."

Richard spent the weekend preparing for death. His roommate came by with pictures of Richard's home, dog and garden, as if to distract his eyes from the pitressin IV whose imminent removal might kill him. They each knew that such a moment might come.

said his roommate, but had never discussed it. "I guess we should have," he said. "But it's his decision, and I support it." Richard himself had no desire for long goodbyes. There was no one else he wanted to see. He was estranged from his family. "If we're going to do it," he said, "let's get it over with."

Monday dawned gray and overcast. Doctors removed the IV. Richard did not look like a man consumed with his own mortality. He watched Regis Philbin and Joan Rivers from the 12-inch screen jutting out from the wall. The bleeding did not resume.

Later that week Richard was transferred out of the MICU. He did get more blood—two units—but not to replace any lost by hemorrhaging: it was to boost his red-cell count. He was going home. Ten days after his death sentence, Richard returned to his roommate, his garden and his dog.

It was a sobering reminder of medicine's fallibility. Though there was still little doubt that Richard did not have long to live, when it comes to predicting *how* long, "we're not that good and we never will be," said Woody Weiss. Richard knew that he would be back at Beth Israel. "I just hope it's not too soon," he said. He had been delivered from dying, but death still beckoned. The next time, Richard would have to decide anew whether to follow.

SHARON BEGLEY with MARK STARR at Beth Israel

I do mind dying. But I haven't any choice... My life [is at] a point where it can no longer succeed.

Dutch Survey Casts New Light On Patients Who Choose to Die

By MARLISE SIMONS

Special to The New York Times

RAMSTERDAM
REQUESTS from terminally ill patients for their doctors to bring on their deaths have been honored more openly and tolerated more widely in the Netherlands than in any other country. Yet after almost two decades of quietly accepting mercy killing or suicide as a patient's right, the Dutch knew little about who was choosing to die, why they sought death and who was helping them obtain it.

Now researchers have begun to answer these questions, with sometimes startling results. Patients asking for a doctor's help to kill themselves are typically cancer patients in their early 60's who fear "dependence, loss of dignity, humiliation and pain," a new study shows. The physician who applies the euthanasia in most cases is the family doctor and most of such deaths take place at home, the study says.

Men and women seek to commit suicide in about the same numbers, the researchers found, and people in their 70's and 80's are far less likely to seek death than those a few years younger.

The researchers, from four Dutch universities, studied people who requested euthanasia or help in suicide from 1986 to 1989. Their study is the first far-reaching investigation of an area in which reliable information is hard to come by, said Gerrit van der Wal, a public health inspector and one of the study's authors.

Euthanasia is explicitly forbidden by law, he said, adding, "It's a very emotional event for everyone and it's often done in secrecy."

Anonymous Questionnaires

To conduct the study, reported in the current issue of the weekly Netherlands Journal of Medicine, the researchers sent anonymous questionnaires to 1,042 general practitioners.

Among the 676 physicians who responded, 388 provided extensive details of cases in which they had cooperated to end a patient's life. Of these, many had helped two or more patients kill themselves.

Most deaths had come about through voluntary euthanasia, which the researchers defined as the physician personally killing the patient at his or her explicit request. Usually,

the doctor injects a large dose of barbiturates to bring on coma, following it with an injection of curare to stop the breathing and the heart.

In the case of assisted suicide, the doctor prescribes or provides a large dose of barbiturates which the patient takes with or without the presence of the physician.

As for the patients, 85 percent were cancer patients in the final weeks of their life. The remainder included sufferers of AIDS, multiple sclerosis or other forms of paralysis, heart or cardiovascular diseases, even when known to be painful and deadly, were only rarely a motive to choose death.

The researchers said they were surprised to discover that requests to die were less common among older patients. The average age was 63 years for men and 66 for women, in both cases well below the average age of people dying at home. Euthanasia and physician-assisted suicide were rare above the age of 75 and very rare above 85, the researchers found.

They said it was possible that older people were better able to accept or tolerate the effects of disease. They said further that the older generation might be less informed or less assertive when it comes to requesting euthanasia.

Men and women requested euthanasia or help in committing suicide at about the same rate. Among men, the largest group suffered lung or bronchial cancer and among women, those with breast cancer made up the largest group. Close to 3 percent of the men had AIDS.

While no official statistics are available, the researchers said they had strong indications that doctors in the Netherlands help about 3,000 patients to die every year. This is less than half of the estimates for euthanasia and assisted suicide that have been widely accepted so far. Of these 3,000 deaths, about 2,000 happen at home and close to 1,000 in clinics and hospitals, Dr. van der Wal said.

Cases in nursing homes, he said, are few, no more than 25 per year. The lower numbers in institutions, he added, "may be because the number of people treating a patient is larger and social controls are stronger."

But the research also indicated that the demand for euthanasia was far greater than its application. The study showed that while doctors in the home practiced mercy killing or assisted suicide about 2,000 times a year, they received at least 5,000 requests.

Informal Standards

Though current law calls for 12 years' imprisonment for anyone who "takes the life of another at his or her explicit and serious request," no doctor has been penalized in such a case in more than two decades. Medical experts say they believe the practice is tolerated because it has wide public support, and because physicians have independently established a series of conditions that are believed to be widely observed.

These conditions require that the request to die be made explicitly and preferably repeatedly by a fully conscious patient and that at least one other physician see the patient independently. Experts say that physicians will then apply euthanasia if the patient is terminally ill, has no hope for improvement and is subject to physical or great mental suffering.

But earlier this year, the Ministry of Health, apparently acknowledging the practice, notified all doctors that mental suffering is not an acceptable reason for assisting patients to kill themselves. Specialists believe the main purpose of the letter was to protect psychiatric patients who might not be able to make an informed choice.

Among other key findings by the researchers were these:

- In close to two-thirds of the cases, doctors estimated their patients had two weeks or less to live when they asked to die. The authors noted that a considerable share, — 10 percent of the patients, were thought to have a life expectancy of three months or more, and that in these cases mental suffering was often assessed as greater than pain.

- In 83 percent of the cases, the patients themselves first broached the subject of euthanasia, while in 10 percent, the physicians first raised it. In 7 percent of the cases, relatives or friends first raised the possibility.

- In three-fourths of the cases, less than one month passed between the first and the final request to die, and in many cases death was brought on within a week or less after the final request.

One marked difference in the attitude of the doctors showed up when a patient's life expectancy exceeded several months. When faced with a patient with just days to live, doctors more readily applied euthanasia. But if life expectancy was three months or more, doctors preferred only to assist the patient in taking his own life.

A QUESTION OF MERCY

Richard Selzer is the author of "Mortal Lessons: Notes on the Art of Surgery" and "Imagine a Woman," a short-story collection. This article is part of a memoir to be published next year.

A physician
asks: If
he helps his
friend
die with
dignity, can
he still
live
with himself?

BY
RICHARD
SELZER

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ALMOST TWO YEARS AGO, I RECEIVED A PHONE CALL from a poet I knew slightly. Would I, he wondered, be willing to intervene on behalf of a friend of his who was dying of AIDS?

"Intervene?"
"His suffering is worthy of Job. He wants to commit suicide while he still has the strength to do it."
"Do you know what you're asking?"
"I know, I know."

"No," I told him. "I'm trained to preserve life, not end it. It's not in me to do a thing like that."

"Are you saying that a doctor should prolong a misfortune as long as possible?"

"There is society," I replied. "There is the law. I'm not a barbarian."

"You are precisely that," he said. "A barbarian."

His accusation reminded me of an incident in the life of Ambroise Paré, the father of surgery, who in the 16th century accompanied the armies of France on their campaigns. Once, on entering a newly captured city, Paré looked for a barn in which to keep his horse while he treated the wounded. Inside he found four dead soldiers and three more still alive, their faces contorted with pain, their clothes still smoldering where the gunpowder had burned them.

As Paré gazed at the wounded with pity, an old soldier came up and asked whether there was any way to cure them. Paré shook his head, whereupon the old soldier went up to the men and, Paré recounted in his memoirs, cut their throats "gently, efficiently and without ill will." Horrified at what he thought a great cruelty, Paré cried out to the executioner that he was a villain.

"No," said the man. "I pray God that if ever I come to be in that condition, someone will do the same for me." Was this an act of villainy, or mercy?

The question still resists answering. Last year, a Michigan court heard the case of a doctor who supplied a woman with his "suicide machine" — a

simple apparatus that allows a patient to self-administer a lethal dose of drugs intravenously. Since then, it seems that each day brings reports of deaths assisted by doctors. A best-selling book, "Final Exit," written by the director of the Hemlock Society, now instructs us in painless ways to commit suicide should the dreadful occasion arise. Even the most ideologically opposed must now hear the outcry of a populace for whom the dignity and mercy of a quick pharmacological death may be preferable to a protracted, messy and painful end.

"But why are you calling me?" I asked my friend.

"I've read your books. It occurred to me that you might just be the right one."

I let the poet know that I had retired from medicine five years before, that I was no longer a doctor.

"Once a doctor, always a doctor," he replied.

What I did not tell him was that each year I have continued to renew the license that allows me to prescribe narcotics. You never know. . . . Someday I might have need of them to relieve pain or to kill myself easily should the

occasion arise. If for myself, then why not for another?

"I'll think about it," I said. He gave me the address and phone number.

"I implore you," said the poet.

The conversation shifted to the abominable gymnastics of writing, a little gossip. We hung up.

Don't! I told myself.

DIARY. JAN. 14, 1990

My friend's friend lives with a companion on the seventh floor of an apartment building about a 10-minute walk from my house. The doorman on duty is a former patient of mine. He greets me warmly, lifts his shirt to show me his gallbladder incision, how well it has healed.

"You can hardly see it," he says. That is the sort of thing that happens when I leave my study and re-enter the world. The doorman buzzes me in.

At precisely 4 P.M., as arranged, I knock on the apartment door. It is opened by L., a handsome, perhaps too handsome, man in his late 30's. We recognize each other as presences on the Yale campus. He is an ordained minister. He tells me that he

has made use of my writings in his sermons. In the living room, R. is sitting on an invalid's cushion on the sofa. A short, delicate man, also in his 30's, R. is a doctor specializing in public health — women's problems, birth control, family planning, AIDS. He is surprisingly unwasted, although pale as a blank sheet of paper. He gives me a brilliant smile around even white teeth. The eyes do not participate in the smile. L. and R. have been lovers for six years.

R.'s hair is close-cropped, black; there is a neat lawn of beard. He makes a gesture as if to stand, but I stop him. His handshake is warm and dry and strong. There is a plate of chocolate chip cookies on a table. L. pours tea. L.'s speech is clipped, slightly mannered. R. has a Hispanic accent; he is Colombian.

For a few minutes we step warily around the reason I have come. Then, all at once, we are engaged. I ask R. about his symptoms. He tells me of his profound fatigue, the depression, the intractable diarrhea, his ulcerated hemorrhoids. He has Kaposi's sarcoma. Only yesterday a new lesion appeared in the left naso-orbital region, the area between the nose and eye. He points to it. Through his beard I see another large black tumor. His mouth is dry, encrusted from the dehydration that comes with chronic diarrhea. Now and then he clutches his abdomen, grimaces. There is the odor of stool.

"I want to die," he announces calmly.

"Is it so bad?"

"Yes, it is."

"But how can I be sure? On Tuesday, you want to die; by Thursday, perhaps you will have changed your mind."

He nods to L., who helps him to stand. The three of us go into their bedroom, where R., lying on his side, offers his lesions as evidence. I see that his anus is a great circular ulceration, raw and oozing blood. His buttocks are smeared with pus and liquid stool. With tenderness, L. bathes and dresses him in a fresh diaper. Even though I have been summoned here, I feel very much the intruder upon their privacy. And I am convinced.

We return to the living room. L. and R. sit side by

side on the sofa, holding hands. A lethal dose of barbiturates is being mailed by a doctor friend in Colombia. R. wants to be certain that it will not fail, that someone will be on hand to administer a final, fatal dose if he should turn out to be physically too weak to take the required number of pills. He also wants L. to be with him, holding him. He asks that L. not cry. He couldn't bear that, he says. L. says that of course he will cry, that he must be allowed to. L. is afraid, too, that it might not work, that he will be discovered as an accomplice.

"I am the sole beneficiary of the will," he explains. L. does not want to be alone when the time comes. He has never seen anyone die before. (A minister? Has he never attended a death-bed?) "It has just worked out that way," he says, as though reading my mind. Still, I am shocked at such a state of virginity.

We have a discussion. It is about death as best friend, not enemy. How sensible were the pagans, for whom death was a return to the spirit world that resides in nature. One member of the tribe vanishes forever, but the tribe itself lives on. It is a far cry from the Christian concept of death and resurrection.

R. passes a hand across his eyes as if to brush away a veil. His vision is failing; soon he will be blind. He coughs, shifts on the pillow, swallows a pain pill. He tells me that he has taken all of the various experimental medicines without relief of the diarrhea. His entire day is spent medicating himself and dealing with the incontinence. Despite chemotherapy, the tumors are growing rapidly. His palate is covered with them. He opens his mouth for me to see. Above all, he wants to retain his dignity, to keep control of his life, which he equates with choosing the time and method of suicide. Soon he will be unable to do it.

"But death," I say. "It's so final."

"I want it," he says again, on his face a look of longing. He wants me to promise that I will obtain the additional narcotics that would insure death, if needed. I offer only to return in a few days to talk. R. urges me to think of myself as an instrument

that he himself will use for his reason. An instrument? But I am a man.

The tone turns conspiratorial. Our voices drop. We admonish each other to be secretive, tell no one. There are those who would leap to punish. I suggest that R. arrange for a codicil to his will requesting that there be no autopsy.

JAN. 16

Four in the afternoon. R. answers the door. He has lost ground. His eyes are sunken, his gait tottering. He is in great pain, which he makes no effort to conceal. As arranged, he is alone. L. is to return in an hour. The barbiturates have arrived from Colombia. He shows me the bottles of tablets in the bottom drawer of the dresser. A quick calculation tells me that he has well over the lethal dose. The diarrhea has been unremitting. The Kaposi's sarcoma is fulminating, with new lesions every day.

"I have always counted so much on my looks," he says shyly and without the least immodesty. "And now I have become something that no one would want to touch." Without a pause, he asks, "What if I vomit the pills?" I tell him to take them at a regular pace, each with only a sip of water so as not to fill up too quickly. If necessary, would I inject more medication? "I have good veins," he says, and rolls up a sleeve. I see that he does. There are several needle puncture marks at the antecubital fossa — the front of the elbow — where blood has been drawn. One more would not be noticed.

"When?" I ask him. No later than one month from today. Do I want to choose a date? R. rises with difficulty, gets a calendar from the kitchen. We bend over it.

"Are you free on Feb. 10?" he asks. "It's a Saturday."

"I'm free."

Feb. 10! There is a date!

I ask R. about his life. He was born and raised in Medellín, one of four sisters and three brothers. His mother had no formal education, but she is "very wise." It is clear that he loves her. No, she knows nothing; neither that he is gay nor that he is ill. He has written a letter to be sent after his death, telling her that he loves her, thanking her for all that she has done. In the family, only an

older brother knows that he is gay, and to him it is a disgrace. He has forbidden R. to tell the others. His sisters live near his mother in Medellín. There are 12 grandchildren. She will not be alone. (He smiles at this.)

Had he always known he was gay? He discovered his attraction to men at age 8, but of course it was impos-



sible to express it. Colombia is intolerant of homosexuality. At 17, he went to Bogotá to study medicine. For six years he lived in an apartment with four other students. There was close camaraderie but no sexual expression. It was a "quiet" student's life. After one year of internship in a hospital, he decided against clinical medicine.

It was while working toward a degree in public health at Yale that he met L. The year was 1983. After completing his studies, he was separated from L. for two years, working in another city, although he returned to visit L. frequently. There followed a three-year period when they lived together in New Haven. Shortly after they met, R. began to feel ill, thought he had an infection. He suspected it was AIDS. He told L. at once and they agreed to discontinue sex. Aside from mutual caressing, there has been no sexual contact between them since.

"It was not sex that brought us together," he says. "It was love." I lower my gaze, I who have always hesitated before expressing love.

L. returns. It is the first

day of the semester at Yale. A day of meeting with students, advising, counseling. He is impeccably dressed. He is accompanied by a woman, someone I know slightly. He notices my surprise.

"This is M.," he announces. "She's all right." He places his arm about her waist, explaining that they have been close friends and confidantes for many years. "She is the sister I have always wanted." L. bends to kiss R. on the cheek.

"Chiquito! You are wearing your new shirt," says L. I am alarmed by the presence of M. It is clear that she knows everything. We sit around the table drinking tea.

"Tell me about death," says L.

"What do you mean?"

"The details. You're a doctor, you should know. What about the death rattle?"

"It has been called that." I explain about not being able to clear secretions from the lungs.

"What sort of equipment will we need?"

"Nothing. You already have the diapers."

"R. has to die in diapers?" I explain about the relaxation of the bowel and urinary sphincters, that it would be best.

"I shouldn't have asked." L. seems increasingly nervous. "I'm terrified of the police," he says. "I always have been. Should I see a lawyer? What if I'm caught and put in prison?" He begins to weep openly. "And I'm losing R. That is a fact, and there is not a thing I can do about it!" When he continues to cry without covering his face, R. reaches out to a hand to console him.

"Look," I say. "You're not ready for this and, to tell the truth, I'm not sure I am either."

"Oh please!" R.'s voice is a high-pitched whine of distress. "It is only a matter of a few minutes of misery. I would be dying anyway after that."

L. pulls himself together, nods to show that he understands. I begin to feel that my presence is putting pressure on him; it makes R.'s death real, imminent. I tell him that I am ready to withdraw. How easy that would be. A way out.

"You are the answer to R.'s prayers," he says. "To him you are an angel." But to L. I am the angel of death.

"Of course, I agree to whatever R. wants to do," he says. It is R. who turns racial.

"If it is too hard for you, L., I won't mind if you are not here with me." And to me: "L. simply cannot lie. If questioned by the police, he would have to tell the truth." I see that the lying will be up to me. All the while, M. has remained silent.

We go through the "script" — L.'s word. In the bedroom, R. will begin taking the pills. I will help him. L. and M. will wait in the living room.

L.: "Will we be in the apartment all the time until he dies?"

M. (speaking for the first time): "Not necessary. We can go out somewhere and return to find him dead."

L.: "Where would we go?"

M.: "Anywhere. For a walk; to the movies."

L.: "How long will it take?"

M.: "Perhaps all day."

L.: "What if the doctors notify the police? R. has made no secret of his intentions at the clinic. They have even withheld pain medication because he is 'high risk.'"

Me (to R.): "Next time you go to the clinic, ask for a prescription for 50 Levo-Dromoran tablets. It's a narcotic. Maybe they'll give you that many. Maybe not."

L.: "I simply can't believe they would turn us in, but there's no way to be sure, is there?"

More and more we are like criminals, or a cell of revolutionaries. L.'s fear and guilt are infectious. But then there is R. I stand up to leave, assuring them that I will come again on Sunday at 4 in the afternoon. M. says that she will be there, too. L. hopes he has not shaken my resolve. He apologizes for his weakness.

"We'll talk further," I say. R. takes my hand. "You have become my friend. In such a short time. One of the best friends of my life."

JAN. 17

In the mail there is a note from L. in his small, neat handwriting. He thanks me. Enclosed is a copy of a lecture he had given in 1984 in which he cited an incident from one of my books, about a doctor who, entreated by a suffering patient who wants to die, stays his hand out of mercy. It is strangely prophetic and appropriate to the circumstances.

My nights are ridden with visions: I am in the bedroom with R. We are sitting side by side on the bed. He is wearing only a large blue disposable diaper. The bottles of pills are on the night stand along with a pitcher of water and a glass. R. pours a handful of the tiny tablets into his palm, then with a shy smile begins to swallow them one at a time. Because of the dryness of his mouth and the fungal infection of his throat, it is painful. And slow.

"You're drinking too much water," I say. "You'll fill up too quickly."

"I will try," he says. What seems like hours go by. From the living room comes the sound of Mozart's Clarinet Quintet. R. labors on, panting, coughing. When he has finished one bottle, I open another. His head and arms begin to wobble. I help him to lie down.

"Quickly," I tell him. "We don't have much time left." I hold the glass for him, guide it to his lips. He coughs, spits out the pills.

"Hold me," he says. I bend above him, cradle his head in my arm.

"Let yourself go," I say. He does, and minutes later he is asleep. I free myself and count the pills that are left, calculate the milligrams. Not enough. It is too far below the lethal dose. I take a vial of morphine and a syringe from my pocket, a rubber tourniquet. I draw up 10 cc. of the fluid and inject it into a vein in R.'s arm. The respirations slow down at once. I palpate his pulse. It wavers, falters, stops. There is a long last sigh from the pillow.

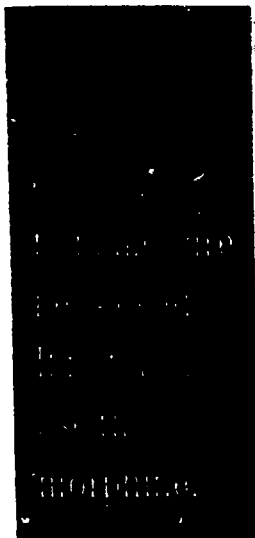
All at once, a key turns in the door to the hallway. The door is flung open. Two men in fedoras and raincoats enter the bedroom. They are followed by the doorman whose gallbladder I had removed.

"You are under arrest," one of them announces.

"What is the charge?" I ask, clinging to a pretense of innocence. "For the murder of R. C." I am startled by the mention of his last name. Had I known it? I am led away.

JAN. 21

M., L., R. and I: R.'s smile of welcome plays havoc with my heart. It is easy to see why L. fell in love with



him. I offer an alternative: R. could simply stop eating and drinking. It would not take too many days. Neither L. nor R. can accept this. L. cannot watch R. die of thirst. There is a new black tumor on R.'s upper lip. He has visited the clinic and obtained 30 Levo-Dromoran tablets. Suddenly, I feel I must to test him again.

Me: "I don't think you're ready. Feb. 10 is too soon."

R. (covering his face with his hands, moaning): "Why do you say that?"

Me: "Because you haven't done it already. Because you've chosen a method that is not certain. Because you're worrying about L."

L.: "I feel that I'm an obstruction."

Me: "No, but you're unreliable. You cannot tell the lies that may be necessary."

L.: "I'm sorry, I'm sorry."

Me: "Don't apologize for virtue. It doesn't make sense."

R.: "There is one thing. I prefer to do it at night, after dark. It would be easier for me." That, if nothing else, is comprehensible. Youth bids farewell to the moon more readily than to the sun.

We rehearse the revised plan. L., M. and R. will dine together, "love each other," say goodbye. L. and M. will take the train to New York for the night. At 6 P.M. R. will begin to take the pills. At 8:30 I will let myself into the apartment. The doorman may or may not question me, but I will have a key. I will stay only long enough to be sure that R. is dead. If he is not, I will use the morphine; if he is, I will not notify anyone. At noon the next day, L. and M. will

return to discover the body and call the clinic. It is most likely that a doctor will come to pronounce death. Of course, he will ask questions, perhaps notice something, demand an autopsy. In that case, L. will show him the codicil to the will. M. asks whether the codicil is binding. At the end of the session we are all visibly exhausted.

FEB. 3

Our final visit. R. is worried that because of the diarrhea he will not absorb the barbiturate. He has seen undigested potassium tablets in his stool. I tell him not to worry; I will make sure. His gratitude is infinitely touching, infinitely sad. We count the pills. There are 110 of them, totaling 11 grams. The lethal dose is 4.5. He also has the remaining Levo-Dromoran tablets. I have already obtained the vial of morphine and the syringe. R. is bent, tormented, but smiles when I hug him goodbye.

"I'll see you on Saturday," I tell him.

"But I won't see you," he replies with a shy smile. On the elevator, I utter aloud a prayer that I will not have to use the morphine.

FEB. 7

Lunch at a restaurant with L. and M.

"It's no good," M. says to me. "You're going to get caught."

"What makes you think so?"

"Why would a doctor with a practice of one patient be present at his death, especially when the patient is known to be thinking about suicide?" She has contacted the Hemlock Society and talked with a sympathetic lawyer. She was told that there is no way to prevent an autopsy. By Connecticut law, the newly dead must be held for 48 hours before cremation, R.'s preference. The coroner will see the body. Because of R.'s youth and the suspicion of suicide, the coroner will order an autopsy. Any injected substance would be discovered. The time of death can be estimated with some accuracy. I would have been seen entering the building around that time. The police would ask questions. Interviewed separately, L., M. and I would give conflicting answers. I would be named. There would be the publicity, the press. It would

be vicious. "No, you're fired, and that's that." I long to give in to the wave of relief that sweeps over me. But there is R.

"What about R. and my promise?"

"We just won't tell him that you're not coming."

"The coward's way," I say.

"That's what we are, aren't we?"

FEB. 11

A phone call from L.: R. is "very much alive." He is at the hospital, in the intensive-care unit. They have put him on a respirator, washed out his stomach. He is being fed intravenously.

"I had to call the ambulance, didn't I?" he asks. "What else could I do? He was alive."

FEB. 15

The intensive-care unit is like a concrete blockhouse. The sound of 20 respirators, each inhaling and exhaling at its own pace, makes a steady wet noise like the cascade from a fountain. But within minutes of one's arrival, it becomes interwoven with the larger fabric of sound — the clatter and thump, the quick footfalls, the calling out, the moaning. Absolute silence would be louder.

From the doorway I observe the poverty of R.'s body, the way he shivers like a wet dog. The draining away of his flesh and blood is palpable. The skin of his hands is as chaste and dry, as beautiful as old paper. I picture him as a small bird perched on an arrow that has been shot and is flying somewhere.

"R.!" I call out. He opens his eyes and looks up, on his face a look that I can only interpret as reproach or disappointment. He knows that I was not there. L. the Honest has told him.

"Do you want to be treated for the pneumonia?" I ask. He cannot speak for the tube in his trachea, but he nods. "Do you want to live?" R. nods again. "Do you still want to die?" R. shakes his head no.

TWELVE DAYS LATER, R. died in the hospital. Three days after that, I met L. on the street. We were shy, embarrassed, like two people who share a shameful secret.

"We must get together soon," said L.

"By all means. We should talk." We never did. ■

Your Continued Involvement in This Issue

There are several possible levels and means of involving yourself in this issue: you may wish to engage in further dialogue about the ethical and policy considerations, you may wish to ensure that your own death or the death of someone else is consistent with your wishes or beliefs, or you may wish to influence public policy in a specific direction. These types of involvement are not necessarily exclusive of one another. To assist you, we list here a few of the wide range of resources and organizations that are available.

Organizations seeking citizen input on medical ethics

American Health Decisions is a coalition of organizations concerned about citizen participation in health care policy decisions. This network is a good place to start if you want to become more involved in dialogue on this issue.

Below is a list of state organizations that belong to American Health Decisions. The extent to which they concentrate on decisions regarding the end of life varies widely from state to state. If your state is not listed, contact Judy Hutchinson at Colorado Speaks Out On Health for information on a resource package for people wanting to start their own Community Health Decisions project.

Arizona Health Decisions
Box 4401
Prescott, Arizona 86302
(602) 778-4850

California Health Decisions
505 S. Main St., Suite 400
Orange, California 92668
(714) 647-4920

Colorado Speaks Out On Health
Center for Health Ethics & Policy
1445 Market St., Suite 380
Denver, Colorado 80202
(303) 820-5635

Georgia Health Decisions
Eggleston Children's Hospital
1405 Clifton Rd.
Atlanta, Georgia 30322
(404) 378-4764

Acadia Institute
118 West St.
Bar Harbor, Maine 04069
(202) 288-4082

Massachusetts Health Decisions
PO Box 417
Sharon, Massachusetts 02067
(617) 784-1966

Midwest Bioethics Center
410 Archibald, Suite 106
Kansas City, Missouri 64111
(816) 756-2713

Nebraska Health Decisions
Lincoln Medical Center Assoc.
4600 Valley Rd.
Lincoln, Nebraska 68510
(402) 483-4537

Citizens' Committee on Biomedical
Ethics, Inc.
Oakes Outreach Center
120 Morris Ave.
Summit, New Jersey 07901-3948
(908) 277-3858

New Mexico Health Decisions
501 Carlyle Blvd.
Albuquerque, New Mexico 87106
(505) 255-6717

New York Citizens' Committee
350 Fifth Ave., Suite 1118
New York, New York 10118
(212) 268-8900

The Right to Die

Bioethics Resource Group
118 Colonial Ave.
Charlotte, North Carolina 28207
(704) 332-4421

Oregon Health Decisions
921 SW Washington, Suite 723
Portland, Oregon 97205
(503) 241-0744

Tennessee Guild for Health Decisions
CCC-5319 Medical Center North
Vanderbilt University Medical Ctr.
Nashville, Tennessee 37232-2351
(615) 883-3248

Vermont Ethics Network
103 South Main St.
Waterbury, Vermont 05676
(802) 241-2920

Center for Health Ethics and Law
University of West Virginia
107 Crestview Dr.
Morgantown, West Virginia 26505
(304) 598-3484

Wisconsin Health Decisions
Lawrence University Program in
Bioethics
Box 599
Appleton, Wisconsin 54912
(414) 832-6647

Advocacy organizations

1. The Hemlock Society is a nonprofit organization that advocates the legalization of active euthanasia. It describes itself as an education organization [that] supports the option of active voluntary euthanasia (self-deliverance) for the advanced terminally ill mature adult, or the seriously incurably physically ill person." It publishes documents about current laws and provides advice for terminally ill patients wishing to end their own lives. The president of the Hemlock Society, Derek Humphry, is author of the recently published *Final Exit: The Practicali-*

ties of Self-Deliverance and Assisted Suicide for the Dying.

The Hemlock Society
PO Box 66218
Los Angeles, CA 90066
(213) 391-1871

2. The Society for the Right to Die/Concern for Dying is a nonprofit organization that provides advice about patients' rights in specific situations and files briefs in court cases having to do with the right to die. Since Living Wills and Durable Powers of Attorney vary from state to state, as do laws concerning the right to die, the organization apprises its members of current regulations. It also publishes a newsletter for its membership. (Annual membership is \$15.)

Society for the Right to Die/
Concern for Dying
250 W. 57th Street
New York, NY 10107
(212) 246-6973

3. Americans United for Life is a nonprofit, public-interest law firm and educational organization. It describes itself as "the oldest national pro-life organization in America, . . . committed to defending human life through vigorous judicial, legislative and educational efforts since 1971." Active in a number of right-to-life issues (most commonly the abortion issue), it takes a position against active euthanasia and the removal of nutrition and hydration from incompetent patients. It has represented the interests of patients whose families wish to remove life-prolonging treatment. It publishes numerous materials on the euthanasia issue. (For a publication and price list, contact AUL.)

Americans United for Life
343 S. Dearborn Street, Suite 1804
Chicago, IL 60604
(312) 786-9494

Suggestions for Leading *The Right To Die*

All discussion groups are different. The participants, the dynamics of your particular group, and the nature of the subject at hand make this so. The following suggestions are not intended to be definitive, but rather to offer general guidelines to help structure discussions using this material.

The aim of small-group discussion is for participants to learn from each other. When the policy issue under discussion is primarily an ethical concern, as is the case in this program, discussion is prompted by and in turn generates strong and deeply held feelings. This makes for special kinds of challenges and potential rewards for the group. The leader's job is to create an atmosphere respectful of all feelings and to challenge the participants to go beyond their individual opinions in order to give full consideration to alternative points of view. If you are successful as a leader, the participants should be unable to identify your personal viewpoint on the subject even at the end of the discussion.

Some general notes on leading discussions on issue of ethics and public policy

- Sometimes when people hear arguments against their own positions, they become involved in attempting to refute the arguments rather than listening and understanding the other's point of view. If this is happening in your group, you can encourage the development of listening skills by asking one group member to repeat or paraphrase what another said before responding to it. You may also ask the group to think about what feeling or value may underlie the two differing viewpoints. Asking participants to

build on the ideas of others enhances a cooperative rather than a competitive spirit.

- While people cannot believe something they consider to be false, they must be willing to entertain the possibility that some of their beliefs are, in fact, false.

- Ask group members to imagine themselves as supporters of each of the viewpoints in turn by consciously identifying which underlying beliefs are most compelling. Taking this sympathetic approach to each position can lead to creative re-examination of long-held beliefs and a new appreciation of others' beliefs.

- As with other ethical issues, participants may hold strong beliefs about what would be the right thing to do in their own personal lives. Working through these beliefs with others is only part of the aim of this discussion; the other goal of the discussion is to consider ideas about what our public policy ought to be. Policy will affect the circumstances of individual decisions, and in turn individual beliefs will affect public policy. Make sure that policy questions are part of the discussion by asking participants what they consider to be the rights and responsibilities of society with regard to the issue at hand.

Preparing for the discussion

The introductory letter and "A Framework for Discussion" will give you an overview of the issue and the way it is presented in this material. You should carefully read the rest of the participants' materials several times until you can clearly describe the three positions. Important general advice for leading a discussion is offered in "Leading a Study Circle."

Explaining the ground rules

In order to reiterate to the participants the purpose of this discussion, you may wish to begin by saying something like the following: "My role is to assist in keeping discussion focused and moving along. Your role is to deeply examine your own beliefs by carefully considering the beliefs of others. This means that listening to others is critical. During the course of the discussion, I hope that you will take advantage of opportunities to argue from a point of view that you don't consider your own."

To give a sense of direction for the two-hour session, you may wish to lay out a general plan for how the discussion will proceed:

- 1) a general discussion of how changes in technology have changed our concept of death (remainder of the first half-hour);
- 2) understanding the positions as presented in this material (about half an hour); and
- 3) a critical examination and debate of the positions, and closing (the remaining hour).

Introductions and starting the discussion

Ask participants to introduce themselves; you may wish to ask them to state briefly what prompted them to come to this discussion. (If participants did not receive material prior to the meeting, you might wish to give them a few moments to read the cases described in "A Framework for Discussion.")

What it means to die with dignity is a matter of very personal concern to all of us, and bringing these personal concerns together with ethical and policy considerations is a sensitive and challenging task for the leader. In your sensitivity to participants' concerns, you will assist participants to listen to each other's concerns and beliefs. At the same time, you should assist the group in thinking out the policy implications of their beliefs.

To begin the consideration of the right to die, have the participants reflect on our society's changing concept of death. How have technological changes affected the ways we think about the end of life? What are the major concerns that people today have about the way in which the end of life is managed? To prompt discussion of this second question, you might mention the popularity of the recently published book, *Final Exit* (by Derek Humphry), that gives advice to the terminally ill on how to end their own lives; ask participants for their reactions to the book and to its popularity.

Understanding the positions

In this part of the discussion, your aim is to help the group members to come to an understanding of the positions before they go on to debate the positions' relative merits.

First, give the participants a few minutes to review "A Summary of the Positions." After that, one way to introduce the material is to ask if anyone would be willing to defend one of the positions to the group, even if it is not a position of that person's choice. This kind of role playing can set a tone of openness and encourage the group to consider unpopular opinions. At this stage of the discussion, other participants may ask questions to clarify the content of the positions, but debate should wait until all four positions have been presented.

Discussing the positions

At this point, ask participants to discuss the positions based upon their actual preferences. A thorough exploration of the positions will reveal a complex set of presuppositions underlying the views and a variety of implications that follow from them. Leaders might want to ask participants which of the supporting points seem most persuasive for each of the positions, and why. "Suggested Discussion Questions" may come in handy for you during this part of the discussion,

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especially if the group (or the vocal part of it) is reaching early consensus. Each participant should feel comfortable to express a minority opinion; there should be no feel of a "hidden agenda." Your questions should assist the members in thinking about the strengths and weaknesses of each position, and in thinking about the possible policy implications of each of the three.

Reaching consensus is not the goal of this discussion. Disagreement is likely to be more constructive, however, when you aid the participants in seeing any important areas of agreement they may have.

Closing the discussion

A good way to close the discussion is to ask whether anyone's views have changed or become more clear to them during the course of the discussion. This closing question has the advantage of providing an opening for those who came into the discussion without a clear stand and who may have been quiet through most of the discussion.

Encourage participants to continue discussing this issue with others. Call their attention to the section of the material entitled "Your Continued Involvement in This Issue."

Finally, thank the participants for attending and ask them to fill out and return the "Follow-up Form" on the back cover of the packet.

Suggested Discussion Questions

In the course of the session, to guide discussion or to bolster flagging conversation, the leader may choose to ask participants to consider some of the following questions.

Starting the discussion

1. How have technological advances forced us to change our concept of death? For example, compare the kinds of medical decisions you might have to make as you near the end of life with the typical decisions people had to make 50 or 100 years ago.

2. *Final Exit*, a recently published book by Derek Humphry, gives advice to the terminally ill on how to commit suicide; it rapidly became a best seller, even without much advance publicity. Do you approve or disapprove of the publication of this book? Why or why not? Reflect on the reasons for its popularity. What do you think that this demonstrates about our society's values and about public policy regarding the right to die?

Understanding the positions

1. *Of any position, ask:* What are the strongest arguments in favor of this position?

2. *You might ask a participant to "take on" the perspective of a position he or she does not agree with. Ask the role player to use the strongest possible arguments underlying that viewpoint to defend it.*

3. *Of any position, ask:* What public policy would follow from this position?

Discussing the positions

1. Suppose that there is a case in which the physician regards further treatment as futile, and yet the patient wants to continue

the treatment anyway. Does the patient have the right to receive treatment and, if so, at whose expense?

2. Consider a case in which the doctor thinks that treatment would benefit the patient and yet the patient wishes to refuse the treatment and be allowed to die. Does the patient have the right to deny treatment?

3. Killing is *usually* considered to be morally wrong; that is, most people will allow for certain exceptions (for example, for self-defense). Do you consider euthanasia to be a permissible exception to the immorality of killing? (*You may wish to refer to some of the cases in "A Framework for Discussion" in order to elicit responses from the group.*)

4. For more than ten years the Netherlands has tacitly allowed for assisted suicide and active euthanasia, though technically both are against the law. (*Recent research on euthanasia in Holland is described in an article reprinted from The New York Times, included in the supplementary reading.*) How does Holland's experience affect your opinion of the argument that allowing for euthanasia will put society on an inevitable course toward killing those society deems unworthy of living?

5. What is the obligation of the physician, especially when the following commonly assumed obligations may be in conflict: to do no harm; to do everything possible to prolong life; to respect the patient's wishes; to relieve suffering. How do we decide which of these should be the most important?

6. What rights, if any, does society have with regard to its members' decisions about the right to die? What responsibilities, if

The Right to Die

any, does society have with regard to those decisions?

7. Who should decide for society the answer to the ethical questions we have been considering? In what ways are you satisfied or dissatisfied with the regulations that currently exist?

8. When is letting someone die morally equivalent to assisting in the person's suicide?

9. Under most current medical standards in the U.S., allowing someone to die is considered permissible under certain circumstances, while actively assisting a person in dying is never considered permissible. The removal of extraordinary treatment (now usually defined to include feeding and hydration tubes), though an "action," is usually considered to be the same as passively withholding treatment. Do you think that these are valid moral distinctions?

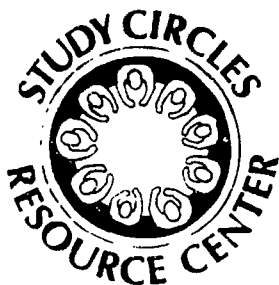
10. Position 3 presumes that it is a violation of the right to life not to sustain life. How would the endorsement of this position in public policy affect society's allocation of resources?

Closing the discussion

1. What are the main points of agreement and disagreement that have emerged during this discussion?

2. Have your views on the right to die changed or become more clear to you as a result of this discussion? In what ways?

3. What advice would you give to policy-makers who are making decisions about this issue?



Leading a Study Circle

The study circle leader is the most important person in determining its success or failure. It is the leader's responsibility to moderate the discussion by asking questions, identifying key points, and managing the group process. While doing all this, the leader must be friendly, understanding, and supportive.

The leader does not need to be an expert. However, thorough familiarity with the reading material and previous reflection about the directions in which the discussion might go will make the leader more effective and more comfortable in this important role.

The most difficult aspects of leading discussion groups include keeping discussion focused, handling aggressive participants, and keeping one's own ego at bay. A background of leading small group discussions or meetings is helpful. The following suggestions and principles of group leadership will be useful even for experienced leaders.

- **"Beginning is half," says an old Chinese proverb.** Set a friendly and relaxed atmosphere from the start. A quick review of the suggestions for participants will help ensure that everyone understands the ground rules for the discussion.

- **Be an active listener.** You will need to truly hear and understand what people say if you are to guide the discussion effectively. Listening carefully will set a good example for participants and will alert you to potential conflicts.

- **Stay neutral and be cautious about expressing your own values.** As the leader, you have considerable power with the group. That power should be used only for the purpose of

furthering the discussion and not for establishing the correctness of a particular viewpoint.

- **Utilize open-ended questions.** Questions such as, "What other possibilities have we not yet considered?" will encourage discussion rather than elicit short, specific answers and are especially helpful for drawing out quiet members of the group.

- **Draw out quiet participants.** Do not allow anyone to sit quietly or to be forgotten by the group. Create an opportunity for each participant to contribute. The more you know about each person in the group, the easier this will be.

- **Don't be afraid of pauses and silences.** People need time to think and reflect. Sometimes silence will help someone build up the courage to make a valuable point. Leaders who tend to be impatient may find it helpful to count silently to 10 after asking a question.

- **Do not allow the group to make you the expert or "answer person."** You should not play the role of final arbiter. Let the participants decide what they believe. Allow group members to correct each other when a mistake is made.

- **Don't always be the one to respond to comments and questions.** Encourage interaction among the group. Participants should be conversing with each other, not just with the leader. Questions or comments that are directed at the leader can often be deflected to another member of the group.

- **Don't allow the group to get hung up on unprovable "facts" or assertions.** Disagreements about basic facts are common for con

troversial issues. If there is debate over a fact or figure, ask the group if that fact is relevant to the discussion. In some cases, it is best to leave the disagreement unresolved and move on.

- **Do not allow the aggressive, talkative person or faction to dominate.** Doing so is a sure recipe for failure. One of the most difficult aspects of leading a discussion is restraining domineering participants. Don't let people call out and gain control of the floor. If you allow this to happen the aggressive will dominate, you may lose control, and the more polite people will become angry and frustrated.

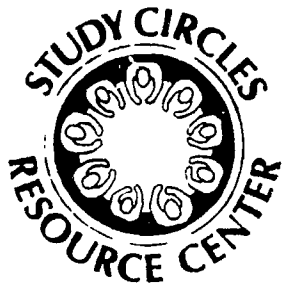
- **Use conflict productively and don't allow participants to personalize their disagreements.** Do not avoid conflict, but try to keep discussion focused on the point at hand. Since everyone's opinion is important in a study circle, participants should feel safe saying what they really think — even if it's unpopular.

- **Synthesize or summarize the discussion occasionally.** It is helpful to consolidate related ideas to provide a solid base for the discussion to build upon.

- **Ask hard questions.** Don't allow the discussion to simply confirm old assumptions. Avoid following any "line," and encourage participants to re-examine their assumptions. Call attention to points of view that have not been mentioned or seriously considered, whether you agree with them or not.

- **Don't worry about attaining consensus.** It's good for the study circle to have a sense of where participants stand, but it's not necessary to achieve consensus. In some cases a group will be split; there's no need to hammer out agreement.

- **Close the session with a brief question that each participant may respond to in turn.** This will help them review their progress in the meeting and give a sense of closure.



Suggestions for Participants

The goal of a study circle is not to learn a lot of facts, or to attain group consensus, but rather to deepen each person's understanding of the issue. This can occur in a focused discussion when people exchange views freely and consider a variety of viewpoints. The process — democratic discussion among equals — is as important as the content.

The following points are intended to help you make the most of your study circle experience and to suggest ways in which you can help the group.

- **Listen carefully to others.** Make sure you are giving everyone the chance to speak.

- **Maintain an open mind.** You don't score points by rigidly sticking to your early statements. Feel free to explore ideas that you have rejected or failed to consider in the past.

- **Strive to understand the position of those who disagree with you.** Your own knowledge is not complete until you understand other participants' points of view and why they feel the way they do. It is important to respect people who disagree with you; they have reasons for their beliefs. You should be able to make a good case for positions you disagree with. This level of comprehension and empathy will make you a much better advocate for whatever position you come to.

- **Help keep the discussion on track.** Make sure your remarks are relevant; if necessary, explain how your points are related to the discussion. Try to make your points while they are pertinent.

- **Speak your mind freely, but don't monopolize the discussion.** If you tend to talk a lot in groups, leave room for quieter people.

Be aware that some people may want to speak but are intimidated by more assertive people.

- **Address your remarks to the group rather than the leader.** Feel free to address your remarks to a particular participant, especially one who has not been heard from or who you think may have special insight. Don't hesitate to question other participants to learn more about their ideas.

- **Communicate your needs to the leader.** The leader is responsible for guiding the discussion, summarizing key ideas, and soliciting clarification of unclear points, but he/she may need advice on when this is necessary. Chances are you are not alone when you don't understand what someone has said.

- **Value your own experience and opinions.** Everyone in the group, including you, has unique knowledge and experience; this variety makes the discussion an interesting learning experience for all. Don't feel pressured to speak, but realize that failing to speak means robbing the group of your wisdom.

- **Engage in friendly disagreement.** Differences can invigorate the group, especially when it is relatively homogeneous on the surface. Don't hesitate to challenge ideas you disagree with. Don't be afraid to play devil's advocate, but don't go overboard. If the discussion becomes heated, ask yourself and others whether reason or emotion is running the show.

- **Remember that humor and a pleasant manner can go far in helping you make your points.** A belligerent attitude may prevent acceptance of your assertions. Be aware of how your body language can close you off from the group.



Follow-up Form

Please take a few minutes to complete and return this follow-up form. Your answers will help us improve the Public Talk Series material and make it a more valuable resource.

- 1) Did you use *The Right to Die*? ☐ yes ☐ no

If so, how? (check all that apply)

☐ in a discussion group ☐ for reference or research material ☐ for lecture or classroom use

- 2) What did you think of the program?

	very good				poor
content	1	2	3	4	5
format	1	2	3	4	5
balance, fairness	1	2	3	4	5
suggestions for leaders	1	2	3	4	5
suggestions for participants	1	2	3	4	5
supplemental readings	1	2	3	4	5

- 3) Please answer the following if you held or were part of a discussion group.

Your role was ☐ the organizer ☐ the discussion leader ☐ a participant

Who was the sponsoring organization (if any)? _____

How many attended? _____

Where was the program held? city _____ state _____

How many times did your group meet to discuss this topic? _____

Participants in this discussion group (check all that apply)

☐ came together just for this discussion

☐ hold discussions regularly

☐ meet regularly, but not usually for issue-oriented discussion

Would you use study circles again? ☐ yes ☐ no

- 4) What future topics would you like to see in SCRC's Public Talk Series?

- 5) Other comments?

Name _____

Organization _____

Address _____

Phone _____

Please return to the Study Circles Resource Center, PO Box 203, Pomfret, CT 06258
or FAX to (203) 928-8713.

See reverse side for information on other Public Talk Series programs.

Public Talk Series Programs and Other Resources Available from the Study Circles Resource Center

Publications of the Study Circles Resource Center (SCRC) include topical discussion programs; training material for study circle organizers, leaders, and writers; a quarterly newsletter; a clearinghouse list of study circle material developed by a variety of organizations; and a bibliography on study circles, collaborative learning, and participatory democracy. Prices for topical programs are noted below. (You are welcome to order single copies and then photocopy as necessary for your group.) Other resources from SCRC are free of charge.

Topical discussion programs

(prices are noted below)

Comprehensive discussion guides

- ___ *Can't We All Just Get Along? A Manual for Discussion Programs on Racism and Race Relations* - \$3.00
- ___ Election Year Discussion Set - \$5.00
 - *The Health Care Crisis in America*
 - *Welfare Reform: What Should We Do for Our Nation's Poor?*
 - *Revitalizing America's Economy for the 21st Century*
 - *The Role of the United States in a Changing World*

Public Talk Series programs - \$2.00 each

- ___ 203 - *Revitalizing America's Economy for the 21st Century*
- ___ 401 - *The Health Care Crisis in America*
- ___ 501 - *Homelessness in America: What Should We Do?*
- ___ 302 - *The Right to Die*
- ___ 301 - *The Death Penalty*
- ___ 304 - *Welfare Reform: What Should We Do for Our Nation's Poor?*
- ___ 202 - *American Society and Economic Policy: What Should Our Goals Be?*
- ___ 303 - *Are There Reasonable Grounds for War?*
- ___ 106 - *Global Environmental Problems: Implications for U.S. Policy Choices **
- ___ 105 - *Facing a Disintegrated Soviet Union **
- ___ 107 - *The Arab-Israeli Conflict: Looking for a Lasting Peace **
- ___ 104 - *The Role of the United States in a Changing World **

* based on material developed by the Choices for the 21st Century Education Project of the Center for Foreign Policy Development at Brown University

Other resources from the Study Circles Resource Center

(available at no charge)

Pamphlets

- ___ "An Introduction to Study Circles" (20 pp.)
- ___ "Guidelines for Organizing and Leading a Study Circle" (32 pp.)
- ___ "Guidelines for Developing Study Circle Course Material" (32 pp.)

Resource Briefs (single pages)

- ___ "What Is a Study Circle?"
- ___ "Leading a Study Circle"
- ___ "Organizing a Study Circle"
- ___ "The Role of the Participant"
- ___ "Developing Study Circle Course Material"
- ___ "Assistance with Study Circle Material Development"
- ___ "What Is the Study Circles Resource Center?"
- ___ "The Study Circles Resource Center Clearinghouse"

Connections (single-page descriptions of ongoing study circle efforts)

- ___ Adult Religious Education
- ___ Youth Programs
- ___ Study Circle Researchers
- ___ Unions

Focus on Study Circles (free quarterly newsletter)

- ___ Sample copy
- ___ Subscription

Other publications

- ___ Clearinghouse list of study circle material
- ___ *Annotated Bibliography on Study Circles, Collaborative Learning, and Participatory Democracy*

Please send in your order, with payment if you order PTS programs,
with your follow-up form on reverse.